Creative Supports for Vulnerable Citizens

Presentations to the Guelph Spring Conference
29 April 2005

Guelph Services for the Autistic

Person-Centred Homes and Support Networks

Guelph Services for the Autistic

Incorporated as a charitable, not-for-profit corporation in 1980, and reorganized in 1997 as a housing trust for adults with Autism Spectrum Disorders. It is not an agency, has no paid staff, and depends on the voluntary efforts of members. Creative support mechanisms being pioneered by GSA are attracting interest and being followed as models.

Important elements of GSA's approach:

1. Focus on the individual person:

- friends and family listening deeply to the person
- person-centred planning and individualized funding
- self-directed plans for good lives in home communities
- choices of how and with whom to live
- encouragement of self-expression by whatever communication modes work most reliably
- adults with whom GSA has housing agreements are the corporation's "active members" (others are associate members)

2. Emphasis on natural social relationships among family, friends and neighbours. GSA recognizes and works with:

- circles of friends/personal support networks
- aroha or incorporated entities of personal empowerment and support (like microboards)
- creative strategies for community inclusion

Current GSA roles and efforts:

1. Trusteeship role in owning and maintaining a home for each adult, with various legal agreements to protect the person. (So far funds are contributed by families, but other options are possible in future).

2. Developing more living support options, such as "anchor" and companion homesharers

3. Recruiting volunteer friends and host families for adults with autism and their families

4. Outreach through ASPIRE and ACES projects, to encourage and empower other families in Waterloo-Wellington-Dufferin region to learn from the experience of pioneers

5. Information through OAARSN (Ontario Adult Autism Research & Support Network) and AAIWW newsletter (***Adult Autism Issues in Waterloo-Wellington***)

6. The Adult Autism Needs Survey is associated with ASPIRE, but also offered more widely to help adults and families measure quality of life. GSA and OAARSN treat data confidentially to generalize current situations and needs of adults with ASD. Long-form and short-form surveys may be completed on paper or online.

7. Sending representatives to workshops and conferences on relevant planning issues

8. Organizing workshops and conferences, and collaborating with organizations who work with and for vulnerable adults, notably in our region Waterloo-Wellington Autism Services.

9. Family-to-family counseling and support

10. Partnerships with groups and organizations who share our vision and values.

Ontario Adult Autism Research and Support Network website (OAARSN) offers information and communication tools, with opportunities for mutual support and encouragement. Click http://www.ont-autism.uoguelph.ca to reach OAARSN main page, then use the buttons and Search to reach the site's features. You may join OAARSN List to receive weekly bulletins.

Contact GSA about any of its roles, or to make a tax-creditable gift, or send news to OAARSN or ***AAIWW***.

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Guelph Services for the Autistic thanks:

- Our keynote speaker and workshop leaders whose edited presentations are reproduced here,
- Representatives of organizations and creative initiatives who set up displays or took part in a poster session,
- Board and community volunteers who gave great service
in staging the conference at Ignatius Jesuit Centre/Orchard Park in Guelph,
- and all participants in the Guelph Spring Conference, 2005.

GSA also appreciates the grant from The Ontario Trillium Foundation to help with some of the conference costs.

Highlights of the Guelph Spring Conference have also been professionally edited into a summary videotape
Creative Supports for Vulnerable Citizens

Contact for more information and to order copies of this booklet or the videotape:
Phone: (519) 821-7424
Email: gbloomfi@uoguelph.ca

Foreword

This booklet consists of the edited presentations at a gathering of Ontario people who want to be creative in supporting good lives with and for adults who are vulnerable because of their differences and special needs.

In organizing the Guelph Spring Conference 2005, we tried to:
1) Focus on planning and implementing the elements of a good life for each person, by learning from each other's values, principles, effective strategies and success stories
2) Offer ideas of creative strategies and networking possibilities that can help people who live with complex challenges of various kinds
3) Attract people concerned with vulnerable citizens in various roles—self-advocates, family members, friends, support workers and aides, case managers, agency board members and administrators, and professionals in various fields
4) Collaborate with various organizations that share our vision ad values—provincially, regionally and locally
5) Be part of a continuing process of thinking, discussion and advocacy that is timely, given the Ontario Government's stated intention to transform its funding and services for persons with developmental disabilities.

This booklet and the associated video of conference highlights are produced especially for those who could not attend, or who wished to be in more than one of the workshops. We have also started the e-bulletin, Creative Supports for Vulnerable Citizens at
http://www.ont-autism.uoguelph.ca/CS-20050815.html

In organizing the conference, and in editing the video and booklet, we have been inspired by two people in particular. One is Andrew, GSA's pioneering active member, from whom we have learned so much. The other is Malcolm Jeffreys of Windsor Community Living Support Services who provided Andrew and our group with an anchor in very turbulent times.

Gerald Bloomfield, GSA President

Contents

page

1. ***Creative Supports That Work: Values, Principles, and Processes***: Keynote address by John Lord 1

2. ***Building Supports with Individuals:***
Workshop by Judith Snow 13

3. ***From Housing to Creating My Home:***
Workshop by Barbara Leavitt 23

4. ***Building Meaningful Supports for Work and Recreation Experiences***:
Workshop by Peggy Hutchison 33

5. ***How Families and Communities Can Make Creative Options Work: The Windsor-Essex Experience***:
Workshop by Marlyn Shervill, Alice Quinlan and Michelle Friesen 45

6. ***Going Home with Awareness:***
Discussion led by John Lord 57

7. ***Displays of Creative Initiatives***:
Notes on 22 organizations or projects that were displayed at the conference 66

Creative Supports That Work: Values, Principles, and Processes

Keynote address by John Lord

This is a challenging topic. It is a really important topic, and very timely, because it speaks to what we might think of as a "new paradigm of disability and community."

So what's a paradigm?

Paradigm refers to "our world view, how we see things." So we're going to talk a lot this morning about different paradigms.

In preparing for today, I started to think, when did I first connect the whole idea of creative supports and community inclusion? I surprised myself in remembering that I was probably about ten or twelve years old. I had a young friend, who I walked to school with. His name was Blair, and sometimes Blair walked to school with two canes, and sometimes he "walked" to school in a wheelchair. And he was a great friend of mine for a couple of reasons. One is, he was really good at science and math, and I wasn't. And he also thought I was very good at hockey, which I wasn't. But he became a very dear friend of mine, and one day his mother said to me, you can't come around anymore. Blair had been in and out of hospital for years. About a month later I learned that Blair had died. And I didn't even go to the funeral. And I think this story of Blair was very powerful to me as a young person growing up, but I think it reflects the old paradigm. It reflects a view that difference is about shame, that difference ought to be about devaluing, that difference ought to be about "out of sight."

My next really extensive experience with thinking about creative supports was when Peggy Hutchison and I adopted our daughter, Karen. She was three and a half years old, and when she arrived in our house with two older kids who were both under seven, at the time, she wasn't toilet trained, she didn't walk, she didn't talk, but she just had this great smile that you could love her just like that. And she didn't do much except sit on the couch, and we called it "blobbing", and we told our other kids, we said, "Now we don't want Karen to blob, so there's only two things you need to always do. One is you always have to involve her in your play, and secondly you have to make sure she's safe." And it was amazing the wonders that that worked, and how many times we'd go in the living room and they'd be on the couch with all of their toys involving her, and passing her things, and it was not unusual to find my son Jesse having her in his arms, going down the slide full speed!

We learned a lot about creative supports as a family. We learned that if you have some principles that are pretty simple, and if you really believe in community, friendship and belonging, good things can really happen. Great things, in fact, can really happen. For those of you who know my daughter now, who is twenty-six years old, and living on her own with support, with an amazing support network of friends and family.

What I'd like to do for the next while, is talk a little bit about some of the values that are underlying this shift to creative supports and community inclusion. What are those values, and how do they really lend themselves to our hearts and our minds? And then I'd like to talk about some of the principles that we can use and that are really central. Principles are in a way, are like conditions, for how we can build a community that is welcoming. And then thirdly I'd like to help us try to begin to decipher the different kinds of supports that people need in their lives. Because my sense is, in the traditional paradigm that we've been using for a long time now, sixty years or more, we get different kinds of support mixed up; we often get community connecting mixed up with community planning, and we get that mixed up with direct support, and we get that mixed up with peer support. So we often get different kinds of support mixed up, and of course, we expect the agencies to do it all. And so what I'm going to challenge us with, this morning, is to say the community

agencies cannot do it all. Instead, lots of other people need to be involved in helping us make it happen.

The Old Story: Stories that Break Your heart

Like me, you will probably know lots of stories in this work that break your heart. I've had the great honour over the last twenty-five years of having many, many opportunities to interview families and individuals with disabilities. And what I find over and over again, is that the traditional supports that we've figured out so well how to provide, often, involve compliance and what I would call clienthood. In many ways, ***the stories that break your heart are part of an old story***. It is an old story, because if you think about it, the eighteenth and nineteenth centuries were about building an industrial society, commodification and things like that. So, it is not surprising that what happened during that period, was that people who were different, or had some difference, were seen as not being very helpful to the industrial society. So, as you know, we built lots of approaches and services that kept people away from community, kept people away from family. And the thing that really is central to the old story, is the idea of compliance. We know now, although it took us a long time to figure it out, that the old story of compliance and obedience does not work. And why not? Because compliance fails to honour the intrinsic self-determination that is within every one of us.

When we ask people to obey, they become lifeless. When we ask people to obey, they often shut down, don't they? Think about your own situations. Have you ever been in a workplace, where you've been told, day after day, and hour after hour, exactly what to do, exactly when to do it, you shut down. You lose your creativity, right? You lose your opportunity to be creative, and to be participatory. And secondly, stereotypes are very much a part of the old story. Think about the stereotypes of disability; many of the stereotypes are not about what is possible, but they are about what is not possible.

Thirty years ago, for example, we believed that people with serious mental health issues could not live in the community. Thirty years ago we believed that children with autism could not learn. And thirty years ago we believed that people with developmental disabilities needed special, segregated work and leisure settings. And we know now that none of these myths were true. So, the old story simply does not work anymore.

One of the most powerful metaphors of what we're talking about with the old story is the metaphor of the waiting list. If you think about it, how many of us, as family members, were coached to believe, that if we just got on enough waiting lists, and if we were patient enough, our time would come. And the supports we needed would come. If we were well socialized, we came to believe that, in fact, the professionals who were figuring all that out, knew exactly what they were doing! And then what happened to many of us is that we became passive. So I think families and individuals waiting and waiting and waiting, is a strong metaphor for the old story. As I've traveled around this province during the last three or four years, I hear over and over again, families saying they are tired of waiting!! This is a powerful sign of change.

We are now going to step into a different kind of mindset, that says we no longer have to wait. We can actually do things; there are lots of things we can do other than waiting, and that is not about depending on that professional voice in our heads that keeps telling us "they must be right." We can begin exploring this new mindset by trusting ourselves as individuals and as families, that we, in fact, can find a new story.

So What is the New Story?

I've been cautiously optimistic over the last twenty years, to see the new story gradually emerging. It is a new story based on hope and based on possibilities. The new story often begins with genuine conversation. Over the years in Durham region, for example, I've met five families here, another five families there, four families over here, sitting every second Monday night, or every second Tuesday

night, to share their stories, to share their thoughts, to share their dreams, to support each other, in a paradigm of hope.

Conversation becomes a way to believe in yourself and to be part of something bigger than your own little world. Conversation expands possibilities.

As another example, the Bloomfield family in Guelph, and many other families in Ontario, are beginning to say to themselves, we can do this differently, we can invite other people in our community to participate with us, in a support circle for our son or daughter. Families are finding that people will step up, and be part of that support circle for our son or daughter. A young man in my own community of Kitchener-Waterloo, with significant support requirements, is supported by some people in the insurance business, who helped him find a job in his local neighbourhood. These new stories are important, because what the new stories do is give us language. Language about possibilities often precedes the changes we want. We often must say what we want quite a lot before we actually go after it!!

As we begin the journey in the new story, we have to remember, as Albert Einstein said, ***"The significant problems we face cannot be solved at the same level of thinking we were at when we created them."*** In other words, you have to change the way you think if you really want to develop creative supports that move people to full inclusion. What is the best way to think about what Einstein is saying? We know in terms of the old story, a lot of people were institutionalized. Just imagine it was your job to move people out of institutions, and you used the same level of thinking that they used when they built the institutions. What would you do? Because you used the same level of thinking, you would end up building lots of smaller institutions, wouldn't you? You would be thinking bricks and mortar, you would be thinking of residential spaces. We have lots of mini-institutions in Canada. And they're not just always twelve or fifteen bed group homes. Sometimes it is three people living in an apartment, and it looks very much like a mini-institution, because the people who developed it used the same level of thinking as the institutional outlook of people years ago.

It is difficult to make the change to the new story, to the new paradigm. And I think we have to honour that it is challenging to change. So criticisms I am making are not about any individuals, but about the systems that we've created that get in the way of change. Part of our challenge today is figuring out what some of those change strategies might be, and then being able to support each other to make them.

Values are Key to the New Story

Two new paradigm values, self-determination and community are central. I have been reading a fair bit about self-determination to try to get a sense of what I could say about it that was different. What I discovered was that there is a whole body of work in biology and philosophy that talks about self-determination as the biological desire of everyone to create. And I think no matter how vulnerable we are, we all want the freedom to choose and create. We also want to have control over things that are within our grasp. Often, when people are struggling to express themselves, they are struggling for self-determination, even though they may express it in all kinds of different ways. ***Self-determination is a very critical value*** that we're going to keep coming back to over and over. It is the ability of people to seek options, to make choices, and to be supported to make those choices.

Community, in some ways, is life's second great imperative. And while self-determination keeps us instinctually focused on ourselves and the choices we make, community propels us out of ourselves. Community extends us to reach out to other people, to seek belonging, to invite other people into our life, whether it's in neighbourhoods, in networks, or places where people come together around common interest. In a sense, if we start with the values of self- determination and community, we have a very

strong beginning point to build creative supports and to build full inclusion in community.

In addition to values, you also need a vision. When you think about where you work, or your family life, what is your vision? Do you have a family vision? Do you have an organizational vision? And do people really understand it? I have noticed in doing a major project across Canada in twenty innovative projects, that two visions keep coming up over and over and over. One is the vision of citizenship and the other is the vision of inclusion. You can think of citizenship as having the rights and the conditions for participation in community life. And inclusion is our ability to be able to actually be full participants in all settings in our communities.

In recent years, what have we learned about these values, and this vision? For one thing, ***we've learned that if we don't get the values and vision right, it is not possible to get the details of everyday practice right.*** Let me say that again. If you don't get the values and the vision right, it's very difficult to get the everyday practice right. If you don't really believe in self-determination, and understand it at a deeply rooted level, you will easily slide back to compliance. Why? Because we've been so socialized, in our communities, in our country, and in our Western world, to believe in compliance for lots of people, and especially people who have been labeled. Think of the vision and the values like an anchor and an intention. The values anchor us very much like our identity – our values ground us in who we are. The vision is our intention of where we want to go. The new story is well anchored in strong values, self-determination and community, and has a strong intention with the vision of citizenship and inclusion.

The New Story Means New Experience and New Metaphors

I have found that one of the best ways to live the new story is to get to know vulnerable people as friends, as neighbours, as fellow citizens. I'm quite astonished when I meet with service provider groups -- I often find service providers who have been working with people for maybe twenty years, and they do not have one friend who is a person with a disability. How do we move away from understanding people as clients, to understanding people as citizens, if we never have a friendship relationship, or if we never have a relationship that is based on equality? So I think one of the best ways to begin to live the new story, is to be a friend.

I want to explore a new metaphor with you, because the metaphor of the waiting list and waiting for professionals to tell us what to do, is strongly based in compliance, isn't it? What would a new metaphor look like? Well, it seems to me, that the ***new metaphor is partly about life itself***. I want you to imagine that you're in a forest, with fauna and animals, and thousands of species, all interdependent and interconnected, and children are playing in the forest. What is it about that forest? There is life, and energy, and there's diversity, and unlike waiting for somebody to tell you what to do, it's alive with creativity, it's alive with action. As Margaret Wheatley says in her book, *Leadership and the New Science*, ***creativity and connection are the essences of life!*** The new story that we're trying to create today needs to reflect that metaphor and that reality.

If creativity is part of the essence of life, then the capacity to create and adapt is universal. We know that all species change, and so as human beings, we need to change too. Part of the new story is not just about them changing, is it? It's not just about families changing, or individuals changing. It's about us changing in reaction to individuals, and families, in reaction to the wider world.

In some ways, building supports that work for people, is a natural part of what human beings do. They want to make things better, they want to innovate, and they want to be creative. Do you know that every burst of creative energy begins with identification of a problem, or an issue? Not enough support people, all the programs are full, how to access community? Think about any of these issues

that we just identified. To find a resolution to any of them is going to require creativity, isn't it? So the next question might be, who could you invite to begin to help you to look at how we can make some changes? And then the third part might be, what questions would you ask, so that those people you've invited together can begin to be creative about a solution? The key is to create the right context, with the right people and the right questions. We know that just the family by themselves is probably not going to solve the problem of not enough support workers, but maybe if we invite some other people together to brainstorm, and think creatively, we might begin to create some solutions.

So, the new metaphor and the new reality about the new story are very much grounded in self- determination and community, and are also grounded in some capacity to be creative.

The Essence of Support in the New Paradigm

From much research I have been involved in over the years, I have identified three components of support for vulnerable people – these are the essence of support in the new paradigm. The first component is purpose. What was the purpose in the old paradigm? The purpose of support was basically protection, which ended up being passivity and compliance. ***In the new story, the purpose of support is to build a good life in community, and to build capacities for citizenship***. There is a lot of power in intention, because when people have intention, they have a strong purpose. Any support that is provided in the new story, needs to be purposeful. So one of the best questions you can ask is what or why. Why are we doing this? What is the purpose? You will become very popular in meetings if you start asking "what is the purpose?" You will have the purpose of building a good life in community in your heart, but it may take others longer to understand and then invest in that purpose.

The second component of support is relationship. Judith Snow says that "the support relationship is like a dance," and both people are moving in the same direction hopefully, and both people know that the vulnerable person is the one leading the dance! So in any support, relationship is critical. ***Support in the new paradigm involves relationship, respect, dialogue and honouring***. Recently there was an appalling story in the Toronto Star about people who required attendant support to get out of bed, to be toileted, and and to eat. These were horrific stories about attendants coming into people's homes and then leaving them sitting on the toilet, or leaving them unattended for hours sometimes. Disrespect, lack of honouring, very poor support relationships: those are certainly abusive. And the research shows that there's far too much abuse in service settings for people who have been labeled.

Process is the third component of all support relationships. It is interesting that modern physics is teaching us that everything is process!! But it seems to me that the field of human services has somehow gotten caught up in an industrial model, that says, everything is about programs and outcomes. And I think what we need to do is think more about process and context in which we find ourselves when we're providing support or when we're receiving support. When we do this, we become reflective about conditions in people's lives, how good process can make a difference, and how small things really matter when we are supporting someone to experience self-determination and community. Consider, for example, how important deep listening is when supporting someone to express themselves, to express their voice!

Eight Key Principles for Building Creative Supports

I have identified eight principles that I think are critical if we want to build creative supports with vulnerable people. In some ways, these principles are pre-conditions for building creative supports. You can also think of these principles as being guideposts and strategies for implementing the values and the vision. Without principles there is no grounding. There are a lot of places that I go to in this province,

where people don't work from principles. They work from a technique, or they work from somebody who told them what to do. Working from principles is different, as you will see by the nature of some of these.

The first principle: The power of decision-making about supports rests primarily with the individual, family and friends. Does implementing this principle require a paradigm shift for some of us? It sure does, doesn't it? Because many of us work in settings where somebody else makes all the decisions about support that me friend needs. But why can't we, as individuals and families, make those decisions?

In 1993, I was part of a team that did the evaluation of the Special Services at Home Program in Ontario. It will not surprise any of you that one of the major findings of that SSAH study was that families really liked the fact that they had control over the supports in their child's life. No surprise! They had control, they could hire their own workers, they could say when people came into their life, and what they should do when they were there. They could train staff in the way they wanted to. Now, since 1993 there have been several other research studies that support how important decision-making is for families and individuals. Also, remember this principle is grounded in the value of self determination.

The second principle: Community is seen as the first resort in building a good life. Again, does this require a paradigm shift for some of us? It does, because many of us have been taught to believe that when we plan with a vulnerable person, that we should think first about the services that they need. Yet, if we believe that community and citizenship are critical values, this principle challenges us to see the strength, capacity, and resourcefulness of community. We need to see community as neighbourhoods, as family, as informal networks, and as the thousands of what John McKnight calls community associations of common interests.

Some years ago in Markdale, a town of about 1200 people in southwest Ontario, I was working with a group to do some planning around community capacity building, which is a fancy way of asking, what is going on in our community, and how can we build on those things. One of the first exercises we did, was to list all the associations of common interest in Markdale, and in a town of 1200, we found almost ninety associations of common interest. There was a stamp collectors group, a sewing club, and there were service clubs, church groups, and on and on and on. Think about it. Think about the capacity of community, to connect somebody's interests with what is happening in the life of community.

The third principle: Dreams and strengths, guide the supports we need. If you were going to provide support to me in some way, you would have to figure out my dreams or intentions and my strengths or my identity. This means you would have to spend time with me. We all dream for something, don't we? Some of us are dreaming for a good friend; some of us are dreaming for a new career, and some of us are dreaming for some way we can express our artistic side. A dream is really a powerful intention. And we all have gifts as well. We are learning that supports work best when they build on gifts and strengths, because it moves us away from a person's deficits. If we build on strengths, it taps our potential. Research in community mental health is showing, in fact, that when you build on strengths, you actually contribute very significantly to people's healing and recovery.

The fourth principle: Planning and facilitation support is independent from service providers and is transformational. One way to think about this complex principle is that we all need somebody in our life, who's unencumbered from the junk that is in our life. I met with a family a few nights ago who were connected with three different service providers, and had a little bit of SSAH money. Does this family need somebody from one of those four agencies to help them figure out their life? I don't think so. This

family needs somebody who is unencumbered from all of those four agencies, somebody who is independent and can stand and really listen, and help the vulnerable person in the family figure out what his/her dreams are, what the intentions are, what the strengths are. Planning support is transformational when it pays attention to dreams and strengths. It can actually transform you, if somebody really listens deeply to you, helps you identify your dreams, and assists you in sorting out some goals and actions that move you closer to your dreams.

Planning and facilitation support that is separate from service provision is a key principle in the new story. This principle enables people to dialogue. It builds capacity for caring and for people genuinely listening to each other. It is interesting, when we think about the importance of this function of planning and facilitation being independent. At Windsor-Essex Brokerage for Personal Supports, facilitators work for individuals and families. In this context, facilitators listen, provide information, provide unencumbered planning support, help you develop a support network, assist you in building a support plan. An independent facilitator has a really important role to play in the new story, and we need to think about how to make this principle happen in every community and in provincial policy.

The fifth principle: Networks of people are supportive, connected, and empowering. We all have networks in our life; some good, some bad, some small, some large. But building creative supports requires that we build a positive network, and this requires that we nurture people in our lives who might care for us. You might say, I know somebody who doesn't have anybody in their life. That is an important question to ask, because now we can be creative in figuring out how can we help that person find one person, or two people that might start to care for them. What are this person's interests? What are their dreams? Where do they hang out in the community? What would they like to do? Can we find anybody in those settings that might come into their life?

People First of Windsor-Essex created the diagram on the next page. People First is a group of vulnerable people themselves, who come together, to support each other and advocate for change. The diagram begins with self determination, as the person is the director. As part of what they call "person-directed planning," a network of support is built in way that the plan becomes the person's story within the context of community, a group of family and friends.

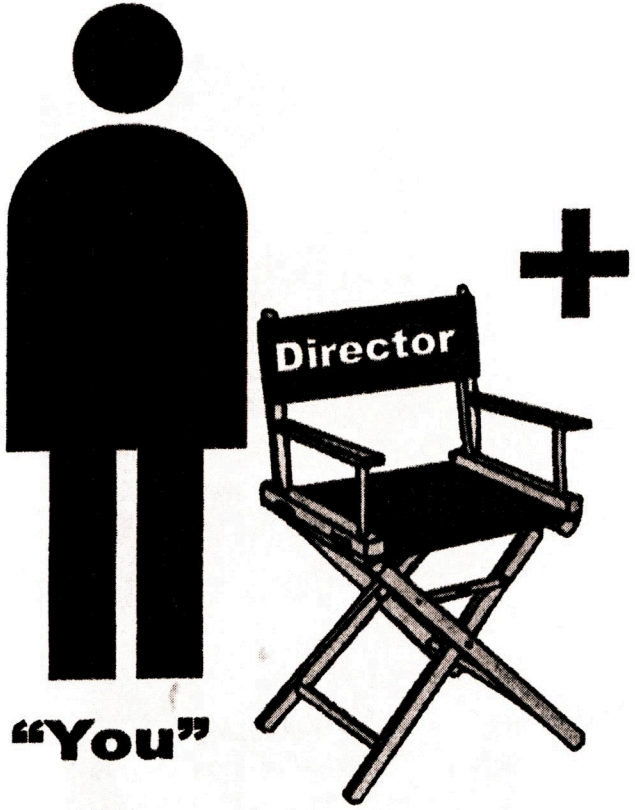
The sixth principle: Funding for support is individualized and portable. Typically, public funding for disability supports is provided by community agencies in what is sometimes called block funding – in the old story, this funding is primarily used for programs and services. This new principle says that funds will be based on a person's plan and goals and it will be designed to meet that person's unique needs.

The seventh principle: Direct practical support is context-oriented and seemingly spontaneous. Wouldn't that be nice? If all practical support had a kind of spontaneity to it and was very context-oriented, it would mean that individualized support would be a perfect fit with the person's goals and needs. We'll talk about that in more detail soon.

The eighth principle: Autonomous groups for families and individuals expand the possibilities for peer support, collective initiatives, and advocacy. In community mental health in Ontario, it has been about twelve years since the Ministry of Health started funding autonomous groups, which they call consumer/survivor groups. People with significant mental health issues are able to come together, provide peer support to each other, and develop initiatives that meet their goals and needs. A new five year research study just published by the Centre for Research and Education in Kitchener shows very powerful impacts of having autonomous groups of people themselves who can come together.

Person-directed planning

"Making decisions, making choices"

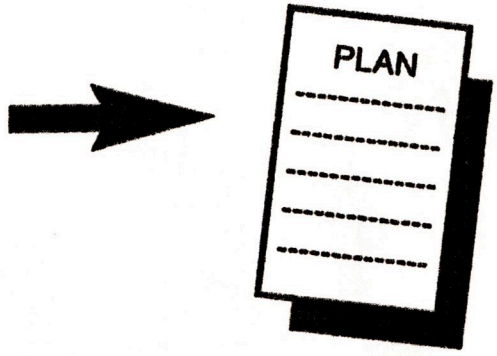


You are the 'director'.

You take the lead. (This may occur by having someone very close to you help with this.) You invite others to assist and help you with your dreams and decisions. You have a right to make your own choices and decisions.

Family, Friends and Others
(Networks of Support)

These are the people you invite to help you with planning. You decide who are the people that are most important to you and who care the most about you. These people will help you make decisions.



Your plan is your story.

It talks about what is important to you and why. It states what you want to do with your life. It describes what you want to do in the future and what help you are going to need.

A budget is attached.

Diagram developed by self advocates and People First of Windsor members - Windsor-Essex Community Planning 2000

I'm sure that research on family, autonomous family groups would say the same. This principle of autonomous groups contributes to how the new story or new paradigm will contribute to system change. The division of functions is central any transformed systems – planning and facilitation are independent of service agencies, as is family support and advocacy.

The New Story and Service System Change

When we look closely at all these principles, it is clear that the current service system needs to change. The service system we currently have is not going to be able to respond to these principles, without significant transformation. At the same time, I hope you are also getting a sense that we can do a lot of this work ourselves. We can begin to have conversations in our communities, with other families, and with individuals. It is no longer about "getting ready" for autonomous family groups, it's about creating them. It is no longer about "getting ready" for independent planning, it is about beginning to do it in a small scale way, community by community. Of course, this doesn't mean that we do not need the government. ***We know from many efforts at social change that these principles work best, are most coherent, and benefit more people when all levels, including government, embrace them and practice them.*** In other words, if we had those eight principles implemented by government, community agencies, and individuals and families, you would have powerful transformational change.

Unfortunately, in the history of human services, this coherence at all levels is rare. It actually happened in community mental health, from 1992 to 1995, when the New Democratic Party was in power; in several Ontario communities, the government principles, the agency principles, and the consumer principle were aligned. Well, we don't have that coherence now, but there are many provincial groups that are seeking change in the way communities and governments provide support, so we can move to more genuine options for families and individuals. There is growing consensus that we need to create systems where functions are clearly separated. As I travel this province, I hear more and more people saying they want independent facilitation and planning support. I hear more and more people saying they want individualized funding. Transformation in the way government works usually comes when there is a groundswell of voices for change. Transformation is usually expanded when current research is consistent with the voices for change. We live in times when these two forces have a chance to come together to influence change!

Discerning What Supports to Use When

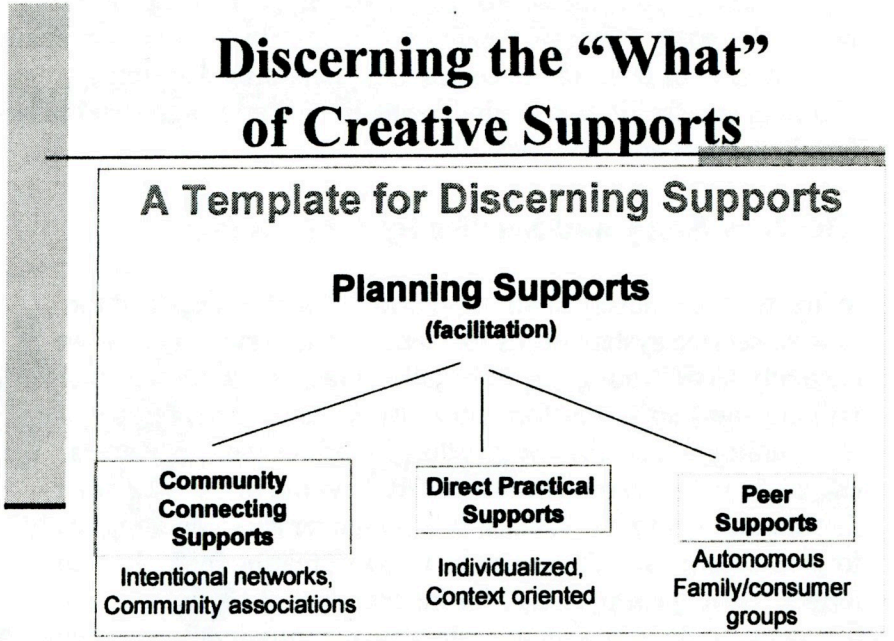
I would like to talk about how we discern what supports to use and when. This is a critical new paradigm issue, because if we are serious about separating functions, we need to know how this might actually work. I created the template below, because in thinking about this issue, what I have noticed over the years, is that in the old story we often get different kinds of support. As an example, one of my daughters was hired through a community agency a few years ago to provide support to an individual. When I looked at her job description, I saw ten things that she was supposed to do. Number ten was "connect people to the community." And do you think she ever did number 10? No. So, we need to become good at discerning what kind of support we need, as individuals or as families, and then being able to dialogue with whoever has the funds and the supports, whether it's agencies or government. We need to get much clearer at that kind of discernment.

Each of these areas of support in the template below requires a separate set of skills and approaches. We need to discern what we are good at and how we can maximize our creativity with the support area we are involved with.

The first part of the template for discerning supports is ***planning supports.*** This is the independent planning and facilitation piece

we talked about previously. With planning support, a facilitator actually assists you in doing some planning about your dreams and your strengths, and how you want to participate in the community, and in what ways you desire to be a full citizen. As we noted, this process involves a lot of conversations among people – facilitator, individual, family, and friends.

So planning and facilitation support facilitators would know the person well, know the community well, listen deeply. You know listening deeply is interesting. We don't do that very well in our field. You know why? I've been thinking a lot about this, and I think it's because when most of us are in a conversation with somebody, what are we doing when the other person is talking? We are thinking about what we're going to say. Part of the idea of being mindful and listening deeply is to let that other stuff go, to let your response go, so that you can really deeply hear what that other person is saying. And so that then you can also ask things that will help that person go even more deeply. Dialogue with respect and planning with the principles are two key elements of planning and facilitation support. Involvement with other kinds of support flow from planning and facilitation supports.



The second kind of support is ***community-connecting supports***. Community-connecting supports are often neglected. To understand this, we need to look at the research on relationships for people with disabilities. People who have been labeled in our society have fewer relationships than other people. And many people are lonely, or isolated. So we need to figure out how to build community connecting supports. These connecting supports are also helpful in building an intentional personal network. It might be helping people connect with different parts of community life, and linking with all of those community associations that I talked about in Markdale. One key with connecting support is to know the person well. How can you help connect me with community life, if you don't know me, if you don't know my dreams, and my strengths and my hopes? If you don't know the friends I have, or the friends that I want to have, and know the community well? If you want to hire a good connector, hire somebody who has a strong, large network, because they will know the community, and they can use their own network to help connect you with the community. What principles that we talked about before, is this really enunciating? The principle of community as a first resort. The community connector is very good at asking; asking, asking. Often as family members, we're hesitant to ask, but it is very good in every family to have one asker. That person can then phone people, and say, "would you mind…," or "could you…?" Every family needs an asker.

Direct practical supports are well understood, but the problem is that we often do not know what it means to individualize them. In the new story, direct practical supports are always individualized.

They're built on the strengths, dreams, and needs of the person, but they are also context oriented. This is because people are going to be in the community in different places. So, it makes sense that the practical support worker will be knowledgeable about different contexts and how they can support the person in the most unobtrusive ways. Practical support in the new story fully honours the directions of the individual and family. I know that this has been hard for some support workers, who have worked in a certain way for years, and now have to change. I also know that many support workers tell me that their job is much more meaningful in this new paradigm, because it is purposeful and focused on relationships and community.

Practical support is based on deep respect and mindfulness. To be mindful really means to pay attention: not only to what's going on out there, but to what's going on inside you. To be mindful means to pay attention to what's going on in your own heart, and not to deny feelings that arise. Imagine that you're going shopping with my daughter Karen. You have sat with her and together you have created a shopping list of things that you're going to buy at the store. You felt positive and peaceful. And then you are in the store, and all of a sudden, Karen starts taking things off the shelf that are not on the list. In the old paradigm, what are you going to do? You're going to say, no, stop! But what are you going to do in the new story? How are you going to relate to her in the new story? You may feel frustration, but you also notice her energy and enthusiasm. The creative support worker that we have stands at the end of the line, and holds her hand, and says, Karen, "look at this, take something from the list." "Hey Karen, look at this!", and redirects Karen to something else. The creative support worker might also have a conversation with Karen about what these other things are, looks at the labels, which is literacy training, and so on. Creativity and spontaneity, and flowing with the person, are an important part of being a direct practical support worker.

Peer support and autonomous family and consumer groups are new in many parts of Canada. If you have ever been to a family group meeting, there is a lot of deep listening! If you've ever had the honour as I have of attending consumer group meetings, there is a lot of deep listening. The philosophy of peer support is that "because I've been there, so when you're talking about your shit, I understand it." When you talk about your anxiety or your frustration, I can relate to that. We are learning that peer support is a powerful adjunct to other types of support. But, it must be autonomous and independent from service provision. When service providers set up family groups, it is not peer support.

This template has implications for how we facilitate citizenship and inclusion. Independent planning supports enable people to have genuine choice and control. And here is what's very interesting. We are learning from a few projects, that when people have really effective planning and facilitation supports, people often have lower expectations for direct practical supports. This is because effective, independent planning and facilitation enable people to build capacity, to connect with community, and to develop a support plan that can be met with informal supports. Paid direct supports become less crucial.

To build citizenship, ***governments also have a key role*** and they need to figure out what they are going to fund. From the year 1960, until about the year 1995, almost all government funding for disability supports in Ontario went directly to community agencies. When we make a more discerned, intentional decision about principles, government funding begins to look very different. So government funding won't go just to agencies anymore, government funding might go partly to independent planning support, might even go to autonomous consumer groups or to autonomous family groups. Government funding will go directly to individuals in the form of individualized funding.

Implications of the New Story

Each of us can play a role in building the new story, by the little things we do, by the values we hold, and by the decisions we make in moving to a vision of citizenship and inclusion.

My daughter has a support circle meeting on Sunday of this week. Karen's circle is a group of people that we started to gather together when she was about fifteen years old, about twelve years ago. At first we met every three months or so, to assist Karen in thinking about her life, and now we meet once or twice a year, mostly around transitions. We have great meetings, great process, and great food! A circle member phoned last night to say he cannot come on Sunday, and he was very apologetic. And this is somebody that Karen's known from church for years, a very important person in her life, but when he can't come to a circle meeting on a Sunday afternoon, he's extremely apologetic, because he wants to be there. Karen's circle, like so many personal network, make a difference for the person and for the people who are part of the network. These folks become ambassadors for citizenship. A support network is a small thing that has huge ripple effects.

Story telling is a very important part of the new story. We need to tell more stories because story telling inspires. When I hear your story, I'm inspired; when you hear my story, you're inspired. It is actually the family leaders across the country, and the consumer leaders across the country that continually inspire me. It's just been amazing. More and more people are living the new paradigm, even though we do not as yet have the policy and funding to support it. By living the new story, we are educating others about the new paradigm. Take time to educate each other. When one individual or family advocates for change, they are doing so for all of us. Advocacy on both small and large issues matters!

The magic of creative supports is that they're always evolving. What is interesting is that what we thought was innovative and creative ten years ago is no longer creative and innovative. And that is OK, because we have learned a lot in ten years, and we're further evolving. Evolution, innovation and creativity are a natural part of the human condition. As Victor Hugo said, ***"There is nothing more powerful than an idea whose time has come."*** The idea of people being in community, the idea of people having opportunities and the right to self-determination, the idea that citizenship is for everybody – all these ideas are really profound ideas whose time has come!

Peggy Hutchison, my life partner, and I have been doing a national study on twenty innovative sites across Canada. One of the things we've found that is very powerful is that most innovation with vulnerable citizens happens at the local level in small projects. Perhaps that is not surprising. So, as we conclude this talk, I urge you to start a small project, and invite other people to join you. Find something in your life, in your family, in your neighbourhood, in provincial policy that needs attention. Small projects are the energy from which we will build the new story for all. In each of us and in all of our communities, there is the capacity to make constructive change. As Ann Mortifee, one of my favourite singers from Vancouver, sings, ***"It is within every one of us to be wise."***

I wish you well on your journey, during the day today and in the future.

Building Supports with Individuals

Workshop by Judith Snow

Nancy Cherry: I have the honour of introducing Judith Snow. I decided to let Judith speak for herself. So in her own words:

I have long struggled with the idea that I am "disabled". I don't experience myself as disabled. Of course, I don't mean that I don't notice that I have very limited use of my body. I am perfectly aware that I don't walk, I require hours a day of assistance to accomplish the simplest of tasks, I struggle to keep breathing adequately and I can't spontaneously hug and kiss friends, lovers and family.

These realities impact me and others around me moment by moment. These realities can't be denied!

What I find to be the REAL struggle is the ever present assumption that this state of "me" -- this way of being -- is somehow a lesser path, a misfortune, a mistake, a disadvantage, an embarrassment.

In the past thirty years more and more people have been claiming our right to be respected as we are. As an example, the Social Model is a theory of disability that is popular in the UK and Canada. It aims to empower us by locating the source of our difficulties in the social and physical environment. This is a very strong idea.

Just the same, in spite of our growing liberation, we still are led to believe about ourselves that our physical, cognitive and emotional differences are impairments. Surely, if I am impaired then one morning I will sober up, and be able to walk about and make my own breakfast. No, this isn't going to happen, nor do I spend time longing for the big change. This is the real me - the only, actual Judith Snow!

Welcome Judith, we're delighted to have you!

Thank you very much, thank you. We have about an hour, which is ridiculous, in a way, but we can do something with one hour for sure. And one thing I do want to talk about for sure, is just what Nancy already said. So she's pretty much helped that part already: that there really is no such thing as disability. So I want to talk about that to some extent. And why would I want to talk about that? Well, because if you really believe there is disability, you're going to screw up constantly. Because there isn't. You get that if you are trying to take the 404 to get to Brampton, you won't get there, right? If you take the 410, or the 10 or something else, you will get there, right? So, thinking that people are disabled, is like taking the 404 to try to get to Brampton. You're just not going to get there, right? You will not ever get exactly what you're looking for.

I know it sounds absolutely crazy, but it's a fact: there is no such thing as disability. Therefore the most powerful thing you can do is give it up. And think what is really true. So I will talk to you about what is really true.

Now, beyond that, I'd like to know what you'd like to know. I do know that Debbie and Jamie are desperate to know how I got individualized funding in 1980, and how they can get it now. So I will talk about that. That's going to take a lot of time, just to say those two things, so I've got time for maybe one or two other things. So what would you like to know? ... Why are you here? So a bit more about how to do circles? Friends? What about friends? Let's start with that, and we'll see how we do.

I wanted to tell you about my sister. My sister has blue eyes, and for 36 years has tinted them. Her eyes are turquoise or green, with tinted contact lenses. Now, the reason she does this, is not because she's a fashion queen, but because she does not like the colour of her eyes. Now how many people in this room do not like the colour of their eyes? So it's kind of a rare thing, to actually not like the colour of

your eyes. Most of us, never even think about it. So, imagine all the people that there are in the world, who have a job or a career, because my sister does not like the colour of her eyes. There's the people who make plastic, the people who make the lenses, the people who put them together, the people who truck the things around, the people who make the boxes that we pack the lenses in, and the plastic cases, the people who make the fluids that you put lenses in, and that you clean lenses with, the people who do the advertising, the people who sell the things in the stores, and the optometrists, who give everybody the permission to do all that, right?

So, tens of thousands of people, in North America, have a job or a career, because my sister doesn't like the colour of her eyes. Now, in English, we call that a gift. When you can create an opportunity for lots and lots and lots of other people, we call that a gift. Now you probably never heard that word in that context before, but you know, why would we like somebody who plays the piano really well? Well, it's because it creates opportunities, right? For people to hear music, to people who make pianos, to people who run concerts, and sell tickets and all that kind of stuff, right. So it's a gift. Or take another example. Somebody who runs really fast, and can cover a kilometer in less than two minutes, or something like that. We call that a gift. So we agree, that's a gift.

Could we turn my sister's gift into a disability? What do you think? Yeah, we could, couldn't we? Tell her it's inappropriate to think like that. Actually there is a step even before that. First of all, you'd tell her it's a disability. If somebody decided it's a disability, tell her" "You have a disability, what you're doing is inappropriate." What else would we do, in order to make it a disability? We'd get lots and lots and lots of people who agree with us. How would we do that? We'd do a scientific investigation, proving that it's a rare phenomenon and somehow screws up my sister, right, apparently.

We'd create an agency that would provide support. What kind of support would we provide to her, do you think? Peer support. Now, we've already noticed that there aren't very many people who don't like the colour of their eyes, so how would we actually provide peer support for my sister? All those who don't like the colour of their own eyes, so they could be brown-eyed people who don't like the colour of their eyes, or green-eyed people who don't like the colour of their eyes, or hazel-coloured people who don't like the colour of their eyes. So we have some room to move, but still, it's pretty rare, right? And so how would we provide peer support?

Yeah, we'd have to bring them from all far places. Maybe we'd find one in Fergus, maybe we'd find one in Forest, maybe we'd find one in Windsor/Essex, and we'd find maybe five in Toronto, so we'd have to bring them all together, right? We'd extend the biological basis of this, and that way we'd have more peer support groups.

So what else would we do? What would we do in the resource centre? We'd give lectures on how it could possibly be that you don't like the colour of your eyes, and then what to do about it, right? What would you do about it? What is the thing we would naturally want to do for a disabled person? That we would naturally want to do for my sister? Fix it, yes, thank you. And how would we fix it? We'd make contacts for her, that is one possible way of fixing it. What's another possible way? So we'd maybe change the colour of her eyes, once and for all, with some degree of risk. Probably the most likely thing we'd try is to change her mind about the whole thing. While we're trying to change her mind, let's say we decide to provide her with tinted contact lenses, who would we get to do that? Who gets to provide my sister with tinted contact lenses?

Why wouldn't just the ordinary optometrist on the corner not get to provide my sister with lenses? She'd need an opthamologist, right, very good. Would it just be any opthamologist? So how would that person get to be a special opthamologist, specializing in not liking the colour of your eyes? The answer in my head is, you send them to school for seven years, right? And you pay them a lot of money. Probably something around $200,000 a year? Because they would really know that my sister doesn't like the colour of her eyes, they would really know then by after seven years, right? So they could

say that she should get tinted contact lenses. Now, couldn't she just buy the tinted contact lenses at Walmart or at Zellers? No, what would she have to do? Oh, so there would be an Internet pharmacy option for that, but what else would she have to do? Be fitted? There's a step before that. Yeah, for sure, she'd have to seen, wouldn't she need a prescription? Wouldn't she need a prescription? From this fantasy $200,000 a year person, anyway, you get my point. What's my point? What does she have? A gift which is very rare. But it actually is a huge opportunity for tens of thousands of other people?

I'll tell you another story.

When I went to high school, there was a young woman who used to like to dive, and she went to the Olympics, three times, in her diving career. What is diving? Diving is parking your body upside down in water, over and over and over and over and over and over ... could you imagine doing that for thirteen years, every day of your life? What would we call that, in the disability world? What did we call it in our high school? We called it sports, we called it lots of things, but think of all the people that were involved in providing Beverly Boyce with the opportunity to be a gold medalist in the Olympics three times. There were the people who made swimming pools, the people who clean swimming pools, the people who decide what's a perfect dive and what's a belly flop, the people who judge it, the people who coach it, the people who transport her around the world, the people who set up the Olympics, and get lots of perks for doing it, all the sporting associations, all the government regulations, all the private fundraising, all the hot dog barbecues to raise money for Beverly, all the ticket sales, all the television crews. Now, does everybody have to be part of Beverly Boyce being an Olympic class diver? So if I go to Pickering District High School, do I have to be a supporter of Beverly? No, but will I likely be a supporter of Beverly? I would be making a difference, what else? It's cool. Everybody gets to be on Beverly's team, if they choose, and it's a cool thing to do.

My point is, I have a very unusual, but perfectly normal physical circumstance. As does Jamie, and the other young woman that I don't know down there. I have a very unusual, but perfectly ordinary physical situation. And because of my very unusual but perfectly ordinary physical situation, I can provide opportunities for tens of thousands of people, to do lots of things they would never get to do, otherwise, like making really fancy wheelchairs, supporting me to get through my day, and what else would they get to do? Go to conferences, write on clipboards, stuff like that. There are certainly some government organizations that are useful to have. There are certainly some local organizations that are useful to have, it's very useful to have some unusual routines in my day, kind of like Beverly Boyce. I have to get up about an hour and a half earlier than most people, so did she, every day, to go parking her body upside down. I do some things with my body that most people don't do. So perhaps what I really am, is extraordinarily gifted.

Well, I am an extraordinary athlete, in my field. In a very limited, but for me, very important field, I am a gift. Now do we know what to do with gifted people, which is my point about Beverly Boyce? Well, do we or don't we? If you suddenly had a gifted person arrive in your network, you know, in a sort of, perhaps a different way, yes. I mean if you have someone who's a classical pianist suddenly arrive in your family, you have to make some decisions and choices you wouldn't otherwise have to make. And you have to round up some resources that you wouldn't otherwise have to have. But do you know what to do, if you're in that situation? You'd do a whole lot more than to treat someone with respect. You see the dollar sign in it, don't you? I mean that's the point about my sister, and her contact lenses. Those people who are pushing those darn contact lenses on all of us, who DO like the colour of our eyes, years before we imagined we might want to change the colour of our eyes, do you know that? I mean, everybody today can go into Zellers or Walmart, right, and choose to change the colour of your eyes if you choose. Am I right? Where do you think that came from? Where do you think that came from? Was that there thirty-five years ago? No, it came because people saw the opportunity in my sister. They saw the

opportunity is the point. The point I'm trying to make right now, is people saw the opportunity in it. Now what would cause people to not see opportunity in difference? What would cause people to stop seeing opportunity, when they see somebody unusual, and interesting, like not seeing the colour of your eyes, or parking your body upside down in water?

What would cause people not to see that? They saw it as a disability, exactly. So the point I'm making, right, is there is no need whatsoever to talk to people about what to do. Because people know what to do, you know? We all know what to do, every single one of us knows what to do. When we don't do what we know to do, it's because somebody is telling us not to. It's because somebody is telling us, this is disability, you should stay away.

And I'm going to prove that to you. Supposing, you heard that I was disabled, and you'd never seen me, you had no idea what my physical or cognitive situation was, all you heard was, Judith Snow was disabled. And Nancy said to you, "Judith Snow is disabled, will you pick her up at the airport?" What would you think? What would you know? What would you know? What would you think? What would you know? Absolutely nothing, right? You would know absolutely nothing. What do people think when they know nothing? That's exactly the point. When you are faced with language that tells you nothing . Get me for what I am saying. I am not saying that there is no one interested or available, I'm not saying that there was a lack of information. What I'm saying is you're actually told a gap, you're given a word that creates a gap in your mind, you're told, quote, unquote, nothing. And when you hear a word like that, what everybody in the world does, is you get scared. Do you follow me?

If you don't understand me, ask me. When you hear language that gives you the impression of nothing, or gap, emptiness, meaninglessness, what you feel is fear. So when I say to you, somebody is disabled, because the word actually means nothing, you will feel fear. What if I said to you, Judith Snow uses a motorized wheelchair, will you pick her up at the airport? What do you think? What do you know? Yeah, do you see that you actually see in your mind, a picture of a wheelchair and the car or the van, and you then are thinking whether or not you will pick me up at the airport? You still may choose not to do so, but do you see that you are already thinking about it? You're choosing. Like Beverly Boyce, when I'm faced with the question, "Will you sponsor Beverly Boyce to go to the Olympics?" I am already choosing, yes or no. And because I go to Pickering District High School, and it's a real cool thing to do, I am about 80 per cent likely to say yes. Whereas if I were to say, Beverly Boyce has an excessive, compulsive habit of parking her body in water, she's disabled, what am I going to say? I don't belong here. That is what I am going to say to myself, I don't belong here.

So if the people that we know, love and care about, are having trouble finding friends, guess why? Is it because they have unusual characteristics? No. It's because we say that the unusual characteristic is a disability, and not only do we say it, but we keep on reinforcing that statement, through all the weird things we do around them. All the processes, all the funny people, all the money we put in weird places, all the strange things we do, around it, creates the impression that people should stay away.

The obvious answer from my point of view, and I'm sitting here as one of the people who has most successfully gotten out of the world of disability, so I think I know, the obvious answer is give up disability. It's a useless concept to start with, it's very, very damaging to the people we care about, it's bloody expensive to the taxpayers, and it's getting us nowhere anyway! So what's the point? Forget it! It's useless!

What is really actually true, is that there are people with unusual characteristics. Perfectly normal. Every generation of people has a few people who can run really fast, twenty-five kilometres and not breathe very hard at the end of it, and a few people like me, who

have a great deal of difficulty sticking out my thumb. And a whole bunch of people like yourself, who can walk three or four miles a day and feel really proud of the fact even though you've only spent most of your life sitting on your butt! Right?

And the same with all of the other unusual characteristics that we've labeled. Not very often people come up this way, but every generation has them. And we create unusual opportunities. Now just because Nancy is trying to write something on the flipchart, but I'll tell you some of the unusual characteristics that people that we label disabled often have. They are highly valuable, in our communities, but we rarely acknowledge the huge value that these characteristics have.

GIFTS AND ASSETS THAT PEOPLE WHO ARE VULNERABLE TO REJECTION COMMONLY BRING TO COMMUNITY

Hospitality

- making people feel happy
- listening
- providing a home, to a tenant, companion or personal assistant

Grounding

- slowing people down, reorienting people to time and place
- leading people appreciate simple things
- causing people appreciate their own abilities

Skillbuilding

- pushing people to be better problem solvers
- causing people to try things they've never done before
- causing people to research things they never encountered before
- improving education
- improving technology

Networking

- reaching out to people and breaking down barriers
- asking questions that everyone else is too shy to ask
- bringing people together who otherwise would never meet

Economic

- providing jobs to people who want supplemental income, like artists
- providing jobs to people who need to work odd schedules like homemakers
- providing jobs to people who otherwise have few or no marketable skills
- filling odd niches

Emotional/Spiritual/Transformational

- stimulating a change in perception
- often modeling exemplary forgiveness
- offering opportunities to do something that clearly makes a difference
- reorienting values from accumulation to relationships

Now I want each and every one of you to be thinking of somebody who has been labeled disabled, just one person. Jamie, you think of somebody other than yourself. Think of somebody else, just one person. You've got that person in mind? Does that person you're thinking of make you feel happy just by being with them? Stick your hands up if just being with that person makes you feel happy? We know a lot of people who are really, really, really, really, really, really, good at, helping other people feel happy. Is that an important gift to have? Do we ever pay people, in the Province of Ontario, to help people feel happy? Of course we do. Well, I'm not talking about labeled only, I'm just talking about that specific gift. Comedians, who else? Let's get off the funny side for a minute. Therapists and customer service people--their major job description is making people feel happy in the face of a total breakdown. How about public relations, how about advertising? There's all kinds of ways that we pay people to make other people feel happy. But these particular people, who seem to be really gifted at it, we rarely actually pay them for their gift, do we?

Here's another one. Think of that person. Is that person a good listener? Put your hands up, for how many of those people are a good listener. So about half of them. Do we ever pay people for that, in our world? How many of those people are really good at breaking down barriers, like ice-breaking skills? Going up to people and asking questions that other people wouldn't ask? Is that ever a useful gift? Sure. How many people are good at collecting things? You're laughing right, but quite a few of the people that we've labeled are really good at collecting stuff, aren't they? Are there any economic opportunities out there for people who collect things? Yeah.

I really, I'm going to tell you two of my favourite stories. They're both about people who could have been labeled. One was labeled, one isn't. One of the most amazing things in this world, is when a person who could have been labeled doesn't get labeled. Somehow their family and their friends have been able to stop that process, and they don't get identified. And yet they still are a person with unusual characteristics. The most amazing stuff happens when that happens. So this particular guy, who's now probably in his fifties, he's a member of the International Association of People who Collect Air Sirens. Air sirens. Now some of you small town people know what an air siren is, it's a large noisy machine, that people would let off at noon, to let the factory workers know it's time to go home for lunch. And also, they still do? And also to bring the volunteer firefighters when there is a crisis and stuff like that. So this guy belongs to an association, when I met him, he'd just got back from Russia--he lives in Wisconsin--where he had been meeting and showing off his collection. Could you imagine what it would take to ship a collection of air sirens, from Wisconsin to Russia? Well he'd just finished doing that, and bringing them back. And displaying them. Well, where I met this guy, was because my wheelchair broke down in Wisconsin, and he, well actually people in his company, fixed it. So here's this guy who's internationally known, and he's also running an electronics company in Wisconsin. Now must of you don't know Wisconsin, or what they do there, they make cheese. That's just about all they do in Wisconsin, they make cheese. So I had to drive an hour and a half, to find a place to fix my wheelchair. Now this guy is also almost completely blind, almost completely deaf, which is probably an advantage when you collect air sirens. And he does weird things, like flicking his hands in front of his eyes. Now, what's my point?

Do I want to collect air sirens? No. Do you want to collect air sirens? No. But in fact, there is an international group of people who do - can you imagine? An International Association of Air Siren Collectors. My point is, that what I think is weird is somebody else's cat's pajamas, and that is always so. I may hate fishing, the person next to me, has a toolbox full of worms. I may love video games, and the person next to me, is trying to create an association to ban them from the Internet. What I think is weird, somebody else loves! And our job in life, is to find the people who love what we love. But what we've been doing in the disability world, is agreeing with the people who hate who we are. And letting them run the show, instead

of running a show of our own. On the basis of: "Who I am, is perfectly fine, thank you very much. Like how the heck can I possibly be anybody else? As if! The whole idea of disability is created on the idea that somehow I could have been somebody else. And this is a mistake. Like how on earth could I have been somebody else? If I were somebody else, I'd be somebody else, I wouldn't be me! Me is me, and that's all there is to it. We are who we are and that's it. For all of us. So our job in life is to find the people who agree with who we are, and make something of it, and if they don't agree with us right now, persuade them, like they did with tinted contact lenses. Persuade them that they should really be more like me, than like who they are. That is our job, everybody's job. That's everybody's job in life.

So I'll go back to the other story. I moved into a housing co-op, in 1993. And in this housing co-op, all fifty-two people moved in, in the same month. Most of us had never met each other before. Now, we all knew each other within three weeks. Knew each other, knew something about each other, could talk with each other, could support each other in some way. How the heck do you suppose that happened? What kind of great community facilitation would it take for 52 strangers in the City of Toronto all to get to know each other in three weeks? What do you think? How many people know they have a common interest with the people in their own apartment building, or do you have a common interest with the garbage collector? Does that mean that you got to know everybody? Probably not, right? But do you think that would get 52 people to know each other? What kind of great facilitation do you suppose we had?

So it was probably something like a social party, or a gathering, right? Who do you suppose put on that social party? It wasn't me, no. So I'll tell you the answer. One of the 52 people that moved into our co-op would go into somebody's apartment without knocking, ask people all sorts of questions, that people normally don't ask each other, go into the next apartment without knocking, tell the person in the next apartment everything she learned about the person in the previous apartment, and then ask the same damned embarrassing questions, in this apartment. Within three weeks we all knew each other. And we're all talking about something. Guess what we're talking about?

Now is that an extraordinary gift or what? And what would we normally label that? Exactly. But my point is, is that she has that gift, and in that context, people started to see that indeed it is a gift. Does that mean that it was really great to have her all the time? Do you think sometimes we were really ticked off? But giftedness is sometimes very difficult to support. Do you think Beverly Boyce's mother loves the fact that Beverly Boyce gets up at five thirty every morning and requires five bathing suits and God knows how much money and extra transportation, do you think her family thinks that's wonderful? Probably not, at five thirty on Sunday morning, right?

Giftedness is always a struggle. Being a classical pianist is always a struggle. So it's not about taking the struggle away. It's about recognizing its value. I've given you only about three of the common gifts. I'll give you a couple more.

The people that you know in your head, that you're thinking of in your head, how many of them have helped you learn something that you never would have learned any other way? How many of you, how many of them have helped you become a better problem solver? How many of them have deepened your appreciation of spiritual matters? How many of them have forgiven you in the face of some really screwy things that you've done? How many of them have helped you appreciate your own abilities? All right. So are these things valuable? Extremely valuable. And they are just some of the things, they're not even the personal gifts that that person may have, they are just the obvious gifts that they have. Now the funny thing is that, even though those gifts are obvious, how often do we talk about them?

You see the reason why disability has such a huge grip on us is because it's in our language. We are always talking about it. The

public conversation that goes on and on and on and on and on is that something is broken, something needs to be fixed, this is a problem, this is a burden, this is expensive, this shouldn't have happened, we should try to get rid of this. If we can't get rid of it, we should try to fix it. If we can't fix it, we should hide it away. In the face of that public conversation, that we all participate in, in the face of that public conversation, for somebody to show up as a valuable contributor, which is what the word citizen means, the word citizen means valuable contributor. For somebody to show up as the valuable contributor that they are, is impossible in the face of that language, that discussion.

And it's really important, if you love and care about somebody--this is getting to the question from person who said: "I've had trouble starting a circle." It's very important for you to get somebody to go through your language with you, and show you, like practicing a real exercise, just how often you are participating in the disability conversation. Because if almost everything you say about the person you care about reinforces their so-called disability, nobody is going to want to be in their life.

But if what you say, is this person has unusual and valuable differences, they're always contributing, these are some of the ways that they're already contributing, they're making people feel happy, they're helping people learn to be better problem solvers, they're bringing people together who would otherwise never meet, they're always offering an opportunity to make a difference. If you say what's true about their unusual differences, people will want to be part of their lives. If I gather a group of people in a living room, or a nice place (it doesn't have to be a living room) and I do that by saying, "I know this person, who's having a struggle, because their unusual gifts are not recognized. And so they've become very isolated and they don't have very many opportunities to contribute in our community, but they are very gifted and these are some of their gifts, you know they are very good at making people feel happy, they're really good at offering people opportunities to do something that makes a difference." If I just say stuff like that, and I say: "Will you come, will you sit in this living room with me, and let's just think together, about what are the gifts that this person has, and how can we have other people in our community know that this person is gifted and actually see their contributions." If I say that, I will have twenty people in that living room, without trying hard.

But what if I say to the same people, the exact same people, "My daughter is mentally retarded, she's physically, severely challenged, she requires a lot of help all day, she hasn't been able to learn very much, I'm afraid that the government is going to drop her down a hole and we're never going to see her again?" If we talk fear, if we talk disability, if we talk a real big problem I don't know how to solve, how many people do you think I'd get in my living room? And if I did get any, how long do you think they'd stay?

If you wanted to make sure that somebody has no friends, you talk disability. And the funny thing is, and I'm not blaming anybody personally, because it's everywhere in the world (I've literally worked in twelve countries, and this is everywhere in the world). So it's not personal to you. But just guess how absolutely ridiculous we're being, and we're blaming other people for the fact that our lives are not great. Would your life be great, if people around you said all the bad stuff about you, all the time? And never talked about the good stuff? Would your life be great if everybody refused to talk about the contributions you're making? You're not allowed to have a resume, sorry, you don't contribute anything valuable, and I refuse to write it down, or tell anybody about it. Would your life be great? No.

So it's all about--I'm sorry it's so simple, but actually it is--it's all about what we say about people. How did they get to be the first person in Canada with individualized funding back in 1980? When they didn't do it? My friend got five hundred people to say good stuff about me, and put it on the desk of the Premier of Ontario. What was he going to do? You know, what was he going to do, when five hundred people said this person has been asking you for eleven years, for money so she can live in the community, and you've turned her down, and she's a good person, and we like her, so give her the money. What's the Premier going to do, when five hundred people say, do it, right? But that's not what we do. We write up our little proposals, and we write disability on every page, and we write disability as big as we possibly can, and we put it through all the channels, which are there to create disability, and then we say nothing happened. That's because disability is designed to make nothing happen, right? Do you see what I'm saying?

It's designed to make nothing happen. That's what it's all about. Dis-ability means not working. So in the world of disability, nothing works. It's not a mystery. So inclusion, citizenship, capacity, assets, gifts, those are all about unusual differences, where people get to contribute to each other. Nothing actually works in the world unless people are different from each other. Difference is the most valuable thing that we have, as people. Let me say that again, so you don't miss it. Because if you get this, you've got everything. What would life be like if we were all exactly the same? It's worse. It's worse. Do you guys remember the birds and the bees in grade five? What would life be like if we were all exactly the same? We wouldn't be here. It wouldn't be possible.

Life is created out of difference. All life is created out of difference. And that means inclusion into community life is created out of difference. Community life is created out of an economy, relationship, and decision making, and all those things require difference to work. Economy requires I've got something you want to buy, or I've made something that we need, or whatever, it requires difference. Relationship requires difference, obviously. And decision-making requires that there are at least two choices, right? Relationships, I mean decision-making is based on difference. So difference is fundamental to community. And here we have people in our lives who have some really interesting difference, so what can they create? Some really interesting community, unusual community.

Say it another way. I cannot live my life biologically or socially without creating relationship. That's actually true of all people, but it's specifically true of me, and people like Jamie. Because if I don't create relationship, I don't get out of bed, right? So I have a huge gift of creating relationships. I have to. I do, for people that read a label are almost without exception, gifted in the area of creating a relationship, in spite of what the label says. What we deny to people, is the opportunity for them to create the kind of relationships that they would create, like my friend who went into everyone's apartment, without knocking. We say you can't do that. Well wait a minute, why can't she? Let's figure out a way that she can do that, that works for all of us, because that is her gift. Let her build the world that she is uniquely able to build. Instead of saying, that your life has to look like everybody else's. Why does it have to look like everybody else's? Maybe there is something important here. I really think that that's true. That the people that we label disabled, have unique differences, that are important to community, and they'd be more important to community, the more we let them to be unique. The more we support people to be different, in exactly the way they are different. Because after all, why fight it? And not only why fight it, but we can build something really interesting around it.

People who are labeled something, become very, very often, when they're allowed to be who they are, when they're supported to be

who they are, and when they're valued for being who they are, when people talk positively about who they are, those people create huge networks around themselves. They bring all sorts of people together, who would otherwise never meet. You know, the person with autism, who walks five, six, ten, fifteen miles a day, and loves it, if we create a world where he can do that, every day, think of all the people he meets, or she meets, and brings together, in community, just because he spends his day walking. Instead of letting that person do that, we stop them, we lock them up. It doesn't make any sense, and it doesn't work.

I have time for one more question before noon.... You're saying that your vision is that five hundred people with unusual abilities got elected? But that we all got elected? That is what you're suggesting? I'm curious what your vision is. How do you see that happening? Probably the wrong person to ask, because I don't think governments should make change. I'm not denying that you have a huge, powerful vision, but like Beverly Boyce, I'm not the one to help. My experience of government is that government is the last to change. And that's not where change happens.

If what you're interested in is creating a huge change, then what I said is: ***"Refuse to talk about disability, but talk about contribution."*** What is it people are already contributing, and how can they contribute it more fully? Now you may find that you know somebody that wants to get elected, and I would get a circle around them, of people that understand that person's gifts, and are willing to talk powerfully about their contributions, and just go like anybody else getting elected.

From Housing to Creating My Home

Workshop by Barbara Leavitt

I'd like to tell you what brings me here today because it's personal and it's about someone I've come to love very much… I met Jeff about 15 years ago. He lived with his parents in Stratford and he and I kind of clicked and started hanging out together - became friends. Jeff would sleep over at my house – he got to know my friends and baseball team. I noticed that Jeff knew a lot of people in town and had a lot of family friends, but that he wasn't often invited out. Jeff's autism affects his life in a way that he doesn't use language in ways that people always understand - he uses thousands of photos to engage people in conversations. So I asked Jeff and his parents, Jean and Bob, about the idea of calling some people together to create a circle of friends. I didn't know anything about it, but thought it made a lot of sense. Jean and Bob didn't want to ask friends and neighbours. I never saw it as a favour: I saw it as an opportunity for other people to get to know Jeff the way I had. However, we've all learned since that we all know Jeff in often totally different ways!

The short version of this story is that about 14 years ago we started a circle of friends and it was focused really just on social stuff and spending time with Jeff. Not long after that I asked Jean and Bob about the plans for long term - Jeff was in his late 20s and their other sons had left home already. Jean said that he was on the waiting list for a group home with the local Association, but she wasn't sure how she would ever be able to 'hand over' her son to the agency. A group home did not make sense to me - where Jeff would have little say about what his life would be like – he'd be dependent on others – having to do group activities.

We began talking about other ways to look at it.... we called the circle together to help. We wrote a vision of what we thought Jeff would want his life to look like when he left home. It was that he would live in a downtown apartment with windows overlooking the traffic and could see people. He would have a roommate who didn't have a disability who he could share life with and who would provide some supports. He would have support workers he chose.

It took several years, but Jeff did move out - initially into an apartment for just a few nights a week. We offered the apartment to respite providers for the other nights to help with the rent. Having other people in his place was not important to Jeff – that wouldn't work for everyone. Eventually Jeff moved to another downtown apartment with a supportive roommate with windows overlooking the traffic. And now he lives in a condominium that his mother owns. Jeff's life isn't perfect. Nobody's is. But it is his life. He's had some different supportive roommates over the years, which have brought different things to his life.

We're going to talk in the next hour about different ways that people live, including the idea of supportive roommates, the idea of supportive neighbours, and those sorts of things, as ways for people to get the support that they need.

So this topic is important to me. And I think it's exciting that we're beginning to think more and more about the new story, the new paradigm, the new ways that people can create home. But I also think it's important, and John touched on it this morning, that we look at some of the history of where we've come from in terms of housing around people with disabilities because I think that we are always in danger of going back to the mistakes we made in the past if we don't pay attention to them. So let's look at some of that history. Many of you may be familiar with the book ***From Asylum to Welfare***, which is a pretty comprehensive history up to 1982 of how services for people with disabilities in Ontario have been structured.

We know that just recently we have a government that has committed to closing the final three institutions in this province. I think this is important, because I think that we need to watch closely that the citizens leaving those institutions don't end up in nursing

homes, and we're seeing some scares around that, and we need to watch that. In my little area of Southwestern Ontario, I know twenty-five year olds for whom the services are saying, "we can't do anything so they need to go to nursing homes." This is scary to me, and we need to make sure that we are pressuring ourselves, as people who love people at risk of being sent off, to not allow that to happen. So this announcement about de-institutionalization is wonderful, and I can't wait until the next overhead, in ten years, where we add the next piece of the story, but we need to be pretty vigilant about watching, that, where people go to, it's about creating homes, it's about those important pieces, that it's not about being shipped into the smaller institutions.

I don't know if any of you are familiar with Pat Worth, the co-founder of People First of Ontario, but he once said that an institution is not just a place, it's the way people think. And John spoke about that this morning as well, that we can create institutional housing for people because of the way we think. And John touched on some of the principles that lead to that kind of institutional thinking, or if they're not adhered to, that can lead to that kind of institutional thinking.

I like this quote from Von Goethe: "He (and I always say she/he) is happiest be he king or peasant who finds peace in his home." You talked about that, in these words here, the sense of well- being, those things. ***What I like about this quote is that it is not a dream of the rich, to have a home. That this is not a new fad for people with disabilities, this is about an eons old, basic human need, that we have, to have these things in our life, that we've named, and to have them around us, to have the control of the space around us, to allow for that. I also believe that it's pretty hard to have a sense of personal peace, if you don't have a sense of control in your life.*** And so, I want to spend a bit more time thinking about what that sense of peace, that sense of control, really is, and the difference between housing and a home.

I think the difference between housing and creating a home is self-determination. One of the key pieces of that is the **freedom to choose**. We don't all get everything we want in our lives, but the significant piece is having the freedom to choose it, and having it honoured, having our preferences and our choices honoured. And having people around you, who care about you, who are going to help get that. The freedom to choose from a wide variety of living arrangements, and we're going to spend some time talking about what some of those different kinds of arrangements are and can be. The control of physical space, one of the litmus tests to me, is the people or person who lives in that home, do they sit around and dream about how to redecorate or renovate it? Like most of us do? It doesn't matter if you rent or not, there's always something you want to be doing in your home, as part of your space. Well, do the people who we're supporting to create homes, do that as well? Choosing what kind of neighbourhood you live in, and who you live with, if anyone. Urban, suburban, rural, whether it's single family house, a townhouse, a condo, a rental apartment. Do you want to own it, or do you prefer to rent? And again, I'm going to share some information about home ownership, because I think that's an area we haven't spent a lot of time on, around, how do we help people with disabilities own their own homes? And yes you can on ODSP. So I think we've got lots of work to do around that.

And here's a biggie. That the freedom to move, and to create a new home, and it doesn't take forever. Because there's not a whole service system trying to figure out the domino effect of you moving. So I think that freedom to choose piece is pretty key to the difference between whether you get 'placed' in housing, or whether you've created a home.

The other pieces are **control**, which you've mentioned, you talked about. The control over the money and resources. One of the means that makes it a little bit easier is through individualized funding. Having the choice about the service provider and staff. Jeff has generally not been part of formal interviewing, it's not his thing.

There *IS* a difference between **housing** and creating a **home**

What is it?

The **freedom** to choose (perhaps with help of family and friends)

- from a wide variety of living arrangements
- control of physical space (renovating, redecorating)
- the kind of neighbourhood to live in
- who to live with, if anyone
- an urban, suburban or rural community
- a single-family home, townhouse, condominium or other
- to own or rent
- to move to create a new home later if wanted (and it doesn't take forever)

The **control** over the money and resources to support yourself

- choosing service provider and staff
- ownership of your bank account (and knowing your favourite teller's name)
- deciding how you spend your time

Access to the kind of **support** you need to live your life

With freedom and control comes the **responsibility** to be a good citizen. This may include:

- maintaining your property and physical space
- helping your neighbours
- volunteering in your community/having a job
- participating in neighbourhood activities
- voting in elections
- accepting consequences

He clearly is in charge of firing though. So, that's what we respect. His mom does the hiring, Jeff does the firing, if needed, which is pretty rare, because they've gotten pretty good at picking people.

Access to the kind of support that you need to live your life, and yes, that includes money, but a huge piece that we need to spend more time on, is the community resources, those relationships, the friendships in our lives, that are the kinds of supports that we need. We cannot devalue the role of staff, because they are critical in people's lives. But they are as staff not the ones who provide rich, meaningful, full lives. We're a means to that. And we're important and we're valuable. But we are not friends, we are not family, that people deserve, all people deserve more relationships. And I think one of the interesting things about the safe and security piece, that we want for our own selves, and that we want for people that we love that might be more vulnerable, is that the safety and security is in having a lot of people who love you, it's in having a lot of eyes and ears in your community looking out for you. It is not in having solely a service provider. That is critical, it's important, but real safety and security is in having lots of people who love you.

Of course, with freedom and control, comes **responsibility** to be a good citizen. That means, if you are going to own your home, you should probably cut the grass or the neighbours won't like you. That you maintain your property and physical space, that you help your neighbours, that you volunteer in your community, that you might have a job, that you are part of neighbourhood activities, that you vote in elections. And that you accept the consequences of not doing those things. Of the neighbours being ticked at you because you haven't painted your fence lately.

Well, let's have a little bit of fun with thinking more about this. I don't know how many of you can actually stay up to eleven o'clock at night to watch David Letterman. I know I don't usually make it, but we do have David Letterman's top ten list of how you know you're in a house and not in someone's home.

OK, number ten ... the phone is answered with more words than hello, as in, Jones Street, Sally speaking.

Number nine ... you're not allowed to come home before three pm, because you just haven't figured out how to get you day supports.

Number eight .... you have to earn the right to have a snack or use the phone. I mean this is amazing that this is still true in many people's lives, that we call their homes.

Number seven ... the house has a name, as in the Main Street House. Now I know that there are people who name their houses, Scarlett did, Elvis did, but most people don't name their house based on the street they live on.

Number six ... spare keys are kept at an agency office without your knowledge or consent. And a lot of people have keys to your place, without your knowledge or consent.

Number five .... paid people don't knock or ring the doorbell when they arrive. It's straight in, to their place of work.

Number four ... family are "allowed" to visit. This is so important: because there is a huge difference between, yes you can come anytime to this house and the absolute assumption that you can go anytime assuming your son/daughter/brother/sister wants you to come anytime. Lots of that might be family culture around some families drop in anytime and in some families you would call first. So, does it reflect the family culture of how people spend time together? When I hear service providers say family are encouraged to visit it seems backwards to me, that it says so much about a sense of ownership about whose home that really is. And paid people call it "my house". You know, "at my house my guys love to go out lots." What does that say?

Number two ... there is stuff just for staff that you are not allowed to go near. And we've gotten really good at hiding those things, into

nice looking cabinets, but there are still big red binders or whatever. Another good example is agencies who put computers in people's homes so that staff can communicate better or fill out forms more efficiently. That's missing the point to me of whose home it is. But they're really about a workplace for staff, and it's hands-off, stay away from those sorts of things.

Number one ... I would like to hear from you? What are some of the ways you know that a house is not someone's home?

Yes, choosing the people you live with, without the manipulation of, 'Come on, you guys really like each other, don't you? It'll work great. Come on, it will, really. You can live together."

Lack of personal possessions. That is such a key one.

When you get to use the bathroom. I haven't heard that one before!

You answer your own door. You know, I get really tired of the excuse, "Well they don't talk." Well then we have an obligation to make sure that speaker phones are on at all times, when we're making doctor's appointments with and for people. And that everything we do, that person is aware of, and part of, even if they physically are not able to answer the phone or answer the door.

Lack of personal space. That's right.

Your personal possessions aren't always safe. Yeah, so you end up hiding them. I know people who still carry their bathroom bag from their bedroom to their bathroom in their home.

Yes, good one. In your own home, schedules revolve around you, routines. And the flow of life, the rhythm of life, is about who you are, not about what works for the shifts of the agency.

You get mail that has your name on it. I remember a guy so thrilled to get 'Dear Occupant', but that had meaning.

DAVID LETTERMAN'S TOP TEN LIST
of how you know you are in a house, not someone's home...

1. [?? ideas suggested by workshop people ??]
2. There is a staff office
3. Paid people call it 'my house' (as in, "over at my house...")
4. Family are 'allowed' to visit
5. Paid people don't knock or ring the doorbell when they arrive
6. Paid people don't take their shoes off
7. The house has a name (as in, "over at Main St. House")
8. There is a schedule on the fridge
9. There's information only paid people know about in a big ugly binder on the table.
10. The phone is answered with more words than 'Hello' (as in, "Jones St., Sally speaking")

You have to find a staff to sign a withdrawal slip.

You have the food you like. One of mine, is who organizes the cupboards? Was it the tallest staff, or was it really the people who are living in the space?

"When can I watch tv?" Asking permission about what you watch. The message on the answering machine, that's good. The name of the group home on the answering machine.

It's very difficult. And one of the keys, I think, is starting from a place of individualizing supports, so that you have built in the flexibility around that, so you never lose that this is about their rhythm of life, and it changes as we get older and it changes as we do different things in our lives, so it's not about the system, and how you have to schedule people, at various times. It needs to be about the rhythm. As Marsha Forest used to say, this is simple stuff, it's just not always easy. It's simple that someone's home should be their home, and we should design supports around them.

And I think that's a really good point, because we could do a whole day on how the word 'choice' has been abused in human services. I think that's why working from principles is critical to this. We may not have named them the way that we're doing here, but we all live and act and are in the world around our principles. So how do we make sure that we're always rooted in that? That we don't let it slip? "Sheesh, I crossed the line today, I over-encouraged, or I think I crossed the line because I didn't try to encourage." It's important that we're always thinking about those kinds of things.

One more. Great, that's such a key one, thank you. Risk taking. I won't ask for a show of hands, but how many in this room, have been divorced, or have changed a relationship in their life? And do people have the same, because that is risk taking too, those kinds of decisions around relationships. But, also, key, and you talked about it here too, is, do people have other relationships in their lives? That aren't just, that key role of staff, and let's not minimize or devalue that role, but are there other relationships to help you, base, to find your own rhythms, based on your interactions with other people, from your community.

Well, that's good. Well you have lots of number ones, that's great. It isn't great, and I hope that someday we could gather again and we'd have trouble remembering what they were. So that is what we will shoot for.
Abraham Maslow said, "To the man who only has a hammer and the tool kit, every problem looks like a nail". And I think that ties into what John was talking about this morning, that if we only build group homes, of course that's what people need. If we only send young people to nursing homes out of institutions, because we haven't figured it out in other ways, of course that's what they need. So that is where we need to pay attention. And by the way, I have been challenged on the source of this quote. Some say it's Mark Twain, so in case there's anyone who knows better than I.

In a few minutes, I'm going to introduce you to some people through their stories, which are in your packages. But first let's talk in a general way about some different choices that people have made, and how they've worked for them.

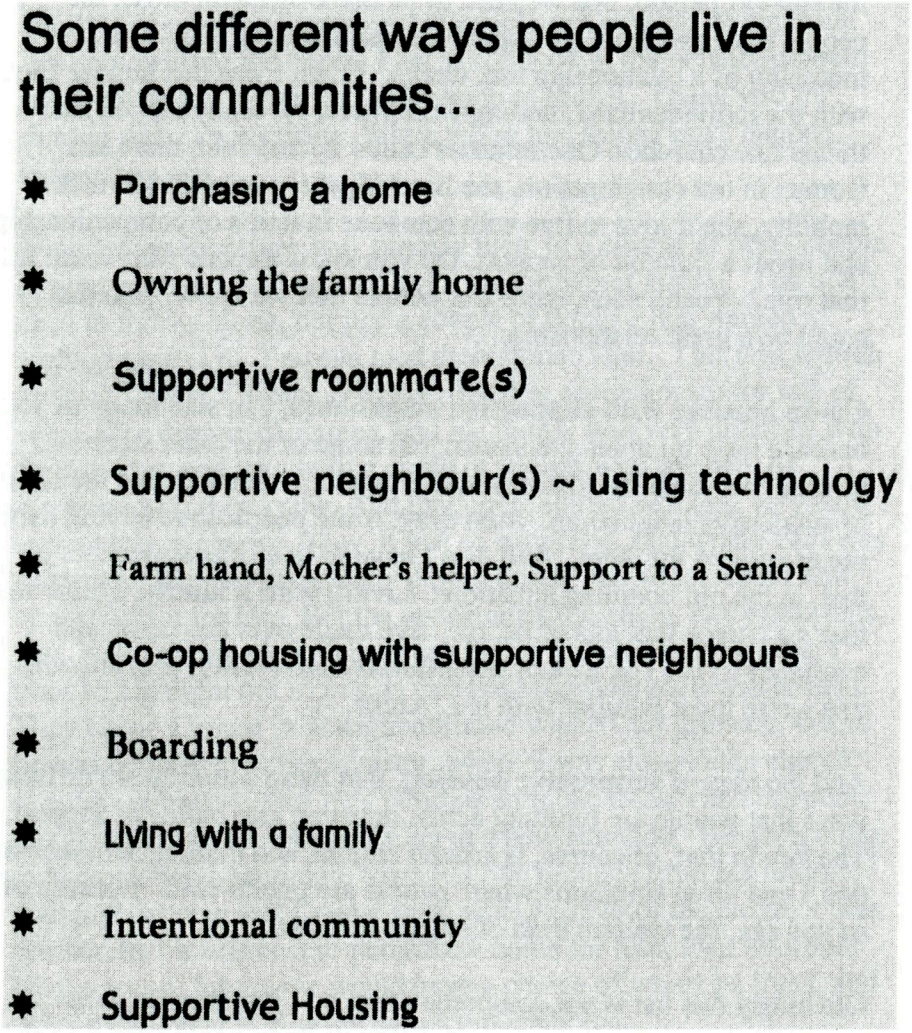
DIFFERENT WAYS PEOPLE LIVE

One of the things we touched a little bit on is the idea of **home ownership**, and it's not something we spend a lot of time in human services talking about. I think it's growing, I think more and more we're seeing families buy homes where their sons and daughters and family members can live long term. But let's talk for a minute about home ownership for people with disabilities, because I think there's lots of myths out there. You can't own a home if you're on ODSP, which is not true. In fact, if you're on ODSP, you qualify for emergency repairs. One of the key things home ownership brings to a devalued person is status, because they're showing up at the rate payers meetings. They know, their neighbours know, they own that house. They're not going to phone some agency and complain about grass cutting. Their neighbour owns the house. What are the other reasons people choose to own their homes as opposed to renting?

An investment for the future. So why do we presume that people with disabilities don't need to invest in their future?

You can't get kicked out. That is critical, because I think that there's lots of different ways home ownership can look. Because what's important to some people is that you can't get kicked out, but the actual idea of actually owning their own home maybe isn't that

important to them, or doesn't make sense at their age, or whatever. But there's other ways home ownership, we can build in, so legal agreements are on sole tenancy, and long term, you can't be kicked out. And get the sense of ownership you can have around your space.


Some different ways people live in their communities...
Purchasing a home
Owning the family home
Supportive roommate(s)
Supportive neighbour(s) ~ using technology
Farm hand, Mother's helper, Support to a Senior
Co-op housing with supportive neighbours
Boarding
Living with a family
Intentional community
Supportive Housing

Neighbours to look after you. You're not a short-term renter, you are one of the home-owners on the street, or in the building. And home ownership is not for everyone, so I would never suggest that everybody should go out and buy a house.

I also wanted to talk briefly, and I'll share some resources around the idea of **rent-to-own**, which is a very long-standing way in Canada that people can, through a long-term agreement for sale, can basically rent-to-own their own home, for a very small down payment. We are lucky in our part of Ontario, to have an amazing man. We call him the John McKnight of Southwestern Ontario, around this, because he is an investor, who is interested in community building. So he has shared with us a lot of ideas around ways that we can help find investors, he being one, who are willing to buy a house and sell it back to Joe, he's not doing double digit stuff. But very, very low down payment. And usually, within about five years, people have put enough equity in and he gets out of it, and they can go to the bank, because they don't require CMHC funding. So, it's a detailed thing, and I've got more resources if you're interested, but I think that we need to start thinking more about home ownership, and different ways that can work. And that includes how housing trusts can play a role as well.

Owning the family home, for those of us who work with lots of people who are getting older, and maybe still living with family, there's always been an assumption that their son or daughter would have to move out when they do, when they either die or have to move into another kind of living arrangement. And that assumption is starting to be challenged and to change. I know one family that has made a legal agreement with the local agency that the daughter will continue to live in the house after her mom passes away. The agency will own it, but she will have long-term tenancy in it and have control over the space and over who she lives with and those kinds of things.

The third idea is around **supportive roommates and neighbours.** I talked a little about Jeff and how it works for Jeff. But I guess what I want to say, with everything, there's always lots of ways that things can work. I've been involved with people where their supportive

roommate has more of a coordinator role, and is actually an employee of an agency. For example, because of their significant and severe medical issues, they want their roommate to have some legitimate authority around staffing and scheduling and things. So, in that situation, the live in Coordinator might have quite separate space in someone's home. Supportive roommates might be living in separate space, rather than actually sharing space. Jeff shares his apartment space. So I guess I just want to say that there's lots of different ways that can work, having supportive roommates. Jeff's roommate gets free rent in exchange for overnight support. Lots of people organize it that way. It comes out of Jeff's individualized funding under supports, that portion of the rent, because it is a direct support to Jeff. And the same with supportive neighbours, particularly with use of technology. We need to spend more time looking at how technology helps people be safe and secure. I'll introduce you to someone whose next door neighbour provides overnight support through the use of technology. There are lots of situations where people are living in duplexes, and a family lives next door, and provide the kinds of support needed.

I think one of the key things people need to think about is how are they going to manage property maintenance, and long-term repairs. I think we can figure that stuff out, because I believe in community. That's your neighbours, that's your family, that's your friends. If you don't have that, then thinking about getting your lawn cut becomes a massive pain in the butt for staff. But that's not how we take care of each other in community. Most of us probably have a senior who lives pretty close down our street, who, we take turns cutting the grass for. Who have family and friends, who we, and where people don't, we need to get intentional about helping them have those relationships. Home is more than just the space for exactly those reasons. So that is a really good point.

I must tell you that I've worked in helping people develop supportive roommates, supportive neighbours in several spots in the province, and I've learned it doesn't matter the size of your town. There are people who this is a perfect lifestyle choice for them. So, we can't say that, well in a small town, you'd never find a supportive roommate. It isn't true. We have to believe, we have to go out and tap into those many associations, in a town of a thousand people.

I think, too, the idea of people being a **farm hand, a mother's helper, a support to a senior** moving in, and living with, maybe as the support person, that we need to be thinking about those, the people that have those gifts and those capabilities. That is a mutuality of a relationship that works. When I was in Thunder Bay, with the individualized funding work there, we really tapped into things like churches. One minister called up and said, there is a woman in our congregation, she has MS, she's got some limited mobility, she'd love to live with someone in terms of companionship and needs a little bit of support. Do you know anyone who could fill that role? Yeah! Yeah, there are, people that we know, who that could be a great relationship.

Co-op housing with supportive neighbours, I'm sure many of you heard, a little bit about Deohaeko and some of the other stories of how people intentionally built space together, that includes the idea of supportive neighbours. **Boarding**, some people love having their meals cooked for them. And don't have to live in basements to do that, in the old boarding situations. **Living with a family**, I think that that's a choice that lots of people have made over the years, and continues to be. The idea of **intentional community**, probably the one we're most familiar with is L'Arche.

And the idea of **supportive housing**, that there certainly are different ways that people are building actual housing, that builds in support. The key to that, of course, is around stigma, and making sure that we don't end up in situations where people are ghetto-ized. Because of, as you say, the welfare kind of stigma attached.

Obviously this list is not comprehensive, so I just wonder, what are some of your experiences around different ways people have worked out where their home is their home, where they have this list you've come up with? Any experiences?

Great. I think it's important when we talk about people living together with families that we avoid it being turned into 'programs'. I am so intentional about not calling it 'associate family', sharing your home, whatever, because it shouldn't be a program to live with people who care about you. The beauty of sharing life with another family, for sure, is something that people can explore. Wonderful! Where you build the house, I bet you'll look at the neighbourhood, and what makes sense, and those sorts of things. Thank you for sharing that, it's inspiring. While we're told things can't happen today, they can.

Well, let me introduce you, quickly then, to a couple of other people. In your package you've got **Carl's Home Sweet Home.** You don't need to follow along, but just a couple of things I just wanted to highlight out if it. You can read their stories later. This was written by Carl's mom, Crystal. And Carl lived in group homes for lots of years after the age of sixteen, and his family was very unhappy with the services, and they built a circle of friends with the help of someone who they knew. And that circle started working very hard to help things change. Now, it just so happened, that where Carl was supported, the agency actually closed down, and so it created new opportunities for him. But the opportunity it created, as Crystal tells you, is that they ended up buying a house for Carl and the thing I want to highlight out of this, is that the neighbourhood was critical. They chose a house in a neighbourhood where Carl grew up, where he was connected to the minister, where it was close to the church and the community that he's familiar with, the library and the pool, that it wasn't about 'placing' Carl in a new situation. He got a house in his own neighbourhood. And it's five minutes from her house. And just the way that Crystal says, with the help of the circle, it was decided that it was best to purchase a home for him, then he would have a secure future, we would have a choice of where he lived, and he was no longer in a group home, but *his* home.

The next one in your package is from **Bill and Richard**. Bill and Richard have lived together for four years. Richard was Bill's support worker for a couple of years before they lived together. And they've been roommates for four years and have a pretty clear agreement about what time Richard needs to be home at night, and compensation in exchange for support, that kind of stuff. The neat thing is that this really is about relationship. Bill and Richard travel together all the time, they've been to Vegas, Nashville, and all over. It really is about relationship.

The next person I'd like to introduce to you through his story is **Nathan**. Nathan lived in group homes most of his life, through the CAS system, and also through ACLs. And really, was very clear through how he was in the world, that he didn't like that. And so he was hospitalized for quite a while, and there was a big flurry about how Nathan could live. We, in fact, when we got to know Nathan, were told that he had to live in a group home, because he just had to learn how to get along with other people. We saw other possibilities and helped Nathan meet a couple who he lived with in a granny flat off of their home. It was on a farm, and yeah, there were lots of issues for a while. It gave Nathan time to discover how he really wanted to live, and what we learned about how he really wanted to live was he would rather live in a town, and in his own place. So Nathan now lives in his own house, in a small town, his next door neighbours are his landlords, and they provide overnight support. He flicks a monitor on at eight o'clock at night, and feels he has the security and support of the next door neighbours. He is venturing out a bit more, and has gotten to know some other neighbours on the other sides and across the street that have also become eyes and ears, and support to him. And he is pretty clear he doesn't want a roommate.

Carrie-Anne lived with her family, moved to a group home, then became hospitalized, ended up in a psych hospital for years, because nobody could figure out how to help her get back home. Eventually Carrie-Anne came home to her own community, in a house. A circle of friends was developed. The house was adapted to meet her needs, which included things like making sure there were safe areas and that there things bolted down to help her be safe. She had a supportive

roommate in the basement who provided overnight support. Carrie-Anne had stopped speaking at the psych hospital, so she had some challenges for sure about getting adjusted again and really around trust. So, she has been home for about three years now. She moved to a home owned by family. Her sisters will tell you that the difference is, for them, is that they can go raid her fridge and flop out on her couch. And they couldn't do that in the group home, and that they feel that, because of the way their family culture is, that is what they do at each other's homes, that they can do it there. Carrie-Anne is pretty involved for sure, she is involved in the hiring of workers, but her family is a key to her choice of workers. They have what we consider individualized funding, because there is a commitment from the agency that it's portable, it's attached to Carrie-Anne. So life is very different for Carrie-Anne, all the adaptations made to the house initially are simply not needed anymore. Life has changed so significantly.

The next story in your package is **Jeff**, who I've introduced you to through my eyes and heart. But his mom has written this so you can get a better sense of it through hers.

And then you can meet **Dave**, who was very thrilled when I asked if I could share this today, because he loves talking about his home. Dave lived with his family for all his life. The home was not accessible, and so it was always difficult helping Dave sort of get around even his own home. Eventually he needed to move out, and so this is a story of how an agency helped, partnership is critical to how people can create a home, how the agency worked with Dave and his family to find investors, and work with the city. They basically worked with a company that did the barrier-free design, the investor paid for the building of the house, the city owns it and subsidizes it, so Dave actually pays rent, a very small amount. It's a duplex, and a family lives next door, who provides support to Dave. Dave interviewed lots of people, in terms of the families next door, and also spent a long time deciding about who he wanted to live with, as a roommate.

And then the last one is about **Andrew**, who lives in Guelph. It's a story around technology and how it can be used to help people create home and live the life that they want to live. There's some really neat stuff in Andrew's home, helps him continue with the rhythms of his life without too much intrusion from workers. And I think Amy, his dog, is a big part of that as well. The house is owned by a housing trust, and they have legal agreements about sole long term tenancy.

In your package you've also got a bit more information on the **rent-to-own** idea. There are a few of us across Ontario who are really interested in this idea and have formed a loose-knit network called the Rent-to-Own Network, where we're really exploring things like how do we work with lawyers who say that people aren't competent to sign legal documents. How do we develop investors in communities across this province who are community-minded?

I just want to wrap up with the quote that John used this morning, ***"The significant problems we face cannot be solved at the same level of thinking we were at when we created them."*** We have to start thinking about these things and not about 'housing' and 'placements'. Life isn't perfect, but it at least has to be yours! So thank you for sharing your thoughts and your experiences and your ideas in exploring this today.

Building Meaningful Supports for Work and Recreation Experiences

Workshop by Peggy Hutchison

Introduction

I am in recreation and leisure studies at Brock University, and have been there since 1990. I teach courses related to diversity. Twenty years ago, we didn't have such courses, but now there's an entire field called diversity studies. I teach courses on aging, gender, ethnicity, community development, and my favourite, disabilities. I am also a parent of four children. John Lord and I are life partners, and you'll be hearing a bit more about our daughter in today's session. We currently live in St Catharines, but also share a home in Kitchener-Waterloo with our daughter. She lives on her own during the week, in a condo that we bought and return to each weekend.

Connecting to Keynote Address and the Shifting Paradigm

Today, we're looking at building meaningful supports for work and recreation. We'll try to build on some of the ideas that John was talking about. We'll make a few connections to the paradigm shift, and then we'll try to apply those concepts specifically to the areas of recreation and leisure and work. I've got lots of experience in recreation and leisure. I'm hoping that some of you here will be able to comment on the employment side. My special expertise is the area of inclusion, the principles of which apply to every area of life.

This picture illustrates the paradigm shift in terms of the change from old to new ways. Change in thinking; change of direction. If you see a picture of something that has an arrow, that says we're going from this to that. So on the left is the old stuff that now we realize is not so good. As you move toward the right on that picture, we're moving more towards things that we consider to be a better way, better lives for people with disabilities, or a better way to organize our services, or a better way to have our communities set up.

Shifting Paradigm

Old Paradigm		New Paradigm
Institutional Supports	Community Agency Supports	Individualized & Community Supports
Patient Role	Client Role	Citizen Role
Isolated from Community	Present in Community	Inclusive Communities

Differences Between Integration and Inclusion

One of the things we're going to try to do is figure out is the difference between integration and inclusion. Are people doing the same thing, but just calling it something different? Or has a paradigm shift really occurred? So let's just look at this picture carefully, to see the fundamental difference between integration and inclusion. Integration is about presence, and inclusion is more about participation. Being valued can happen more with inclusion. Why don't we give some examples of integration and then we'll be able to see why that's a problem and why we've had to come up with this concept to try to push the paradigm a little further along.

In a school, the kids might be in the school: are they in a separate class, or are they in a regular class? With integration they might be in a separate class, but in a regular school, so we do call that

integration? Now you could argue that's segregation, within an integrated setting. But we know that if they're in a separate class in a regular school, it's hard for inclusion to really happen. There are some barriers there. Better than the separate school, for sure. So we know that integration is better than segregation.

So it seems that integration is more about physical presence. Let's say there's a group home on your street. The group home is located in the community, but it doesn't become inclusion unless the people living there are part of the neighbourhood. Research shows that that's going to be a lot easier for inclusion to happen with smaller numbers like two or three than if a group home has seven or eight people. In Kitchener, we've got various group homes, for all different groups, but they are in an industrial area, not in real neighbourhoods. So the potential for inclusion is zero. Now you might ask "isn't this a stepping stone?" Twenty years ago, when we had big institutions, and big services. So we moved people out. But then we started to realize that we had a lot of people who are supposedly integrated into our communities, but their lives had not changed that much. Sometimes the institutional mentality came into the community. So we need different expectations. We came up with a new concept called inclusion.

An Inclusive Community

Many people with disabilities I know spend 95 percent of their time in services for people with disabilities. But most services for people with disabilities are in the old paradigm. They are not what we now understand to be inclusive. Our daughter is not on too many waiting lists for community services, because we don't feel that that's going to help build an inclusive life. We'd rather have no services and no supports, rather than be on waiting lists for something that is not going to head in a direction that we find useful. Let's think about what an inclusive community means.

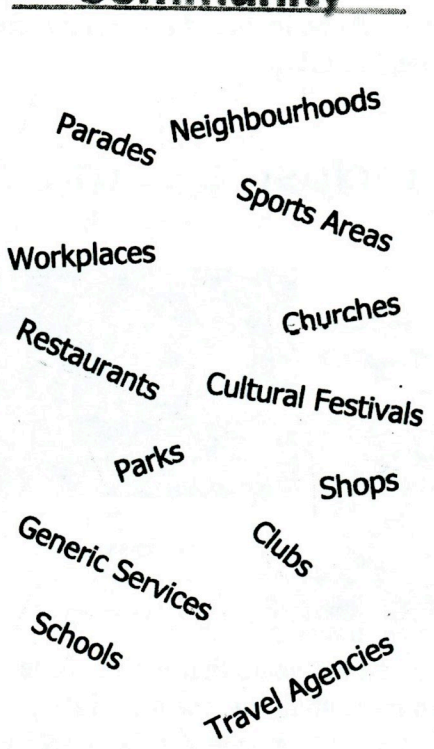
Sees participation in regular schools, workplaces, & recreation settings as a fundamental right

1. The first point here is that it's got to be in regular environments and settings as the bare minimum. It was really full inclusion when my daughter joined her high school swim team and she was in a regular class, at the same time. We can't have inclusion with someone swimming in a small special class at a Y, if there are no other people of that age at that time. In what other regular settings could people be together for inclusion to happen?

2. Looking around in our community, we can see neighbourhoods, sports areas, workplaces, restaurants, cultural festivals and parks. However, we can't just focus on places, or putting people into places, because we've run into trouble with that. We know it is not enough to put a person into a regular neighbourhood, or regular workplace like Tim Horton's. We have to say that is a starting point, but not the end point.

But we have lots of examples in our community that demonstrate we don't get it yet. In terms of the paradigm shift, we still have a way to go. Kitchener-Waterloo still has an institution with a hundred people and a sheltered workshop with a hundred and eighty people who go to that same bus stop at 3:30 every day. So what chance do these persons have for inclusion? And this is not just done to people with disabilities. Visit your family member who is in a retirement home or

nursing home. We see it as a good thing if this place has everything from hairdresser, shopping, and recreation. If those folks had a developmental disabilities, we would say it's an institution and bad, but we now accept this as OK for older folks. So it's going to take us a while to figure out that what we're creating for us boomers, is actually old paradigm.



3. Inclusive settings respect differences by tries to avoid categorizing and labeling people, as can be seen in this cartoon of the rhinoceros.

4. Inclusion prides itself in having all people involved. We've learned that community and inclusion are possible for all persons, including people with severe disabilities. We know that it is said of people in institutions--that they have to be there because they're medically fragile. But we also know that we have family members who are medically fragile who are living in community and having an inclusive life. The people with family members in institutions haven't yet felt what it feels like to have an inclusive life. So the more people that are doing it, the more will learn and be able to share that. *All means ALL* in inclusion. There's no reason why any person cannot be involved. That doesn't mean there aren't challenges: of course there are.

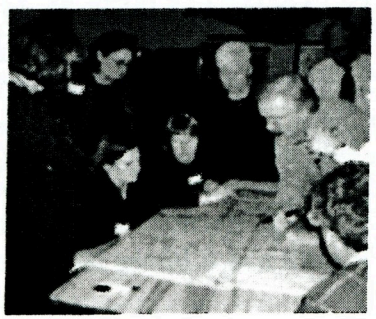
An inclusive community...

Prides itself in having <u>ALL</u> people involved

5. An inclusive community provides opportunities for engagement. That means that people with disabilities just can't be having decisions made for them, for example. It's a paradigm shift--that the people that we're talking about are here and part of the discussion. Twenty years ago, we would have these parent conferences without any people with disabilities.

An inclusive community...

Provides opportunities for <u>engage-ment</u> and involvement

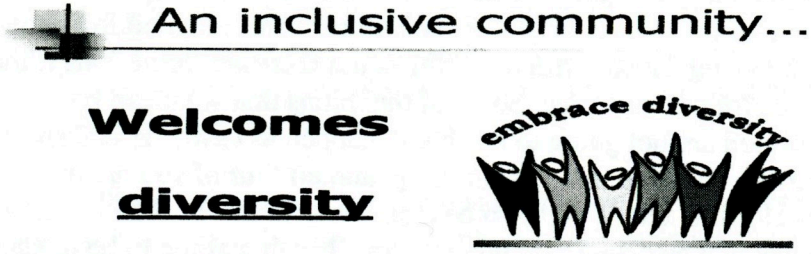


6. Inclusion encourages friendly neighbourhoods.
When we were working for school integration, that's why we had to absolutely insist on the neighbourhood school, where the siblings go to, because that's how people make friends. They walk to school with their friends, or wheel, however they get there. If you've got a group home with four or five people in your neighbourhood, and you can see that they're not fully part of the neighbourhood, what could you do? Are there neighbourhood events, or community-wide events, through which they could be included and encouraged to become really part of that neighbourhood?

An inclusive community...

<u>Encourages friendly neighbour-hoods</u>

7. Inclusion welcomes diversity.
It's only been in the last ten years that we've started to realize that we have to focus on more than just the disability part. With our family member, we've got to ask: What are other important issues? We have to look at issues of age, ethnic diversity and race, and socio-economic issues. A lot of the services have just assumed that everybody is white, English-speaking, and middle class. We should think of these other issues in hiring support or looking for people to be in a support circle.



8. An inclusive community supports people to have networks that provide friendship and support.

Networks that Provide Friendship and Support

We all know people with disabilities who have very few friends and people without disabilities who also have very few friends. This is an issue for everybody in our society. There are many things about our society that create problems for relationships. We live in a transient society. It's very hard for families whose work moves them frequently to have friends. When John and I bought a house down in St Catharines, it would have been easier in some ways just to move Karen, our daughter, down there, but all her friends are in K-W, and her job is in K-W. She has a life in K-W, so we can't just move her down to St Catharines.

The support to have an inclusive life is different from the support for an integrated life. Friends are an important part of that. Spontaneity is an important part of inclusion. On a Friday night, if we want to go to the movie, we might call up friends an hour before. But people with disabilities, say if they're in wheelchairs, need to book public transit a week ahead. If you don't have friends who have cars, you're not going to have spontaneity. We've got to figure out ways so that people with disabilities can be spontaneous.

When you're having a problem, let's say that you've had a fight with your husband, you've got to have a close friend that you can talk to. We can't just use paid supports for everything. If we've got more serious marriage problems, we might go into counseling, longer term sessions. In the short term, who do we count on? We phone our friend and tell them how upset we are, and our friend usually says you'd better come over here right away.

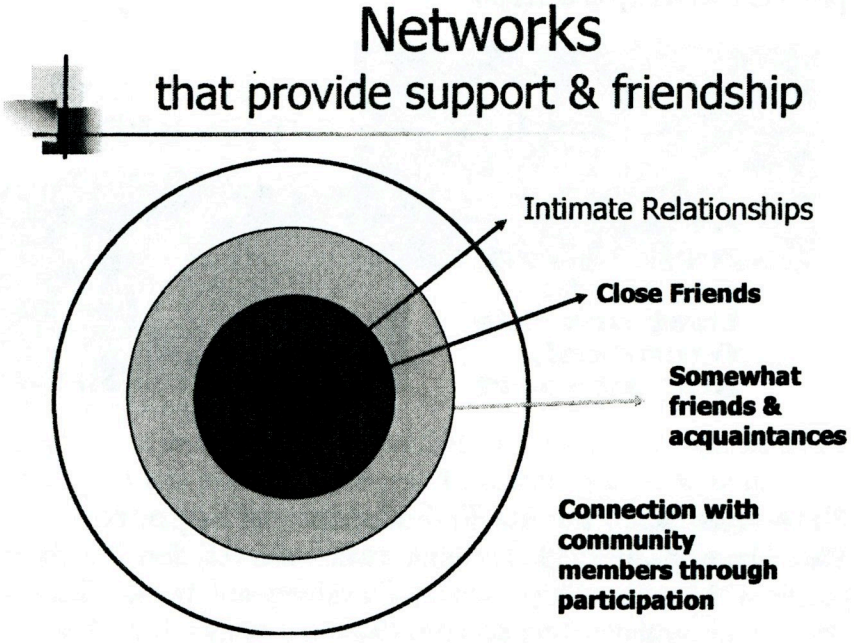
We all need friends to do things with on special occasions. But some people with depression find special occasions very hard and try not to celebrate them. Because they don't have friends, and celebrating special occasions is not exactly fun without friends.

Transience of friends is harder for a person with a disability. It's easier now, if we have things like email. But people often get cut off. How many people here have friends who have moved away, and you stay in touch? You might have figured it out, you fly out there, but it's a pain, it's expensive, it would be a lot better if they still lived in your neighbourhood. People with disabilities have a right to stay connected with their friends.

It's not going to be good enough just to be at work. You've got to take it past that step, make those connections, so that you've got somebody, to do something socially with. We've given our daughter some choices over the years. She has three different workplaces. Only her Tim Horton's job is paid. We've said, each time we've had a circle or planning meeting, do you want more Tim Horton's workdays? And she says, no. Because why would she want to clean the washrooms in Tim Horton's five days a week, when right now, she can do one day a week, and she gets to have the friends that she's made at Tim Horton's. So she says no, she'll keep her volunteer daycare job. She has good friends from there too. Then she's got a third job. In each of those jobs, there are friendships, real friendships. Some of these people have become part of her network, people she does things with outside of work. If she goes to work, then she never sees any of those people in that job, outside of that setting, school or recreation program, then how strong is that setting? Is that an inclusive setting? No. So what can we do? We can try to fix it, or we can move on. Let it go, and see if we can build something more inclusive somewhere else.

Let's have a look at this relationship diagram. Ideally, all people would have people in all circles. In the middle, are very close friends, probably like partners, that would fit into that most intimate circle. Many people with disabilities do not have this opportunity.

In the next circle are close friends. If you've got two or three close friends, then that's good, you're lucky. What if you only have one in that circle? Is that fine? You could loose one. Another thing, there's no choice. If there are four or five close friends, there are still others remaining. Well what about people with disabilities? What if their closest friend is another person with a disability, is that OK, when we're talking about friendships and inclusion? Is that OK for people to have close friends who have disabilities? Yes, of course, a friend is a friend is a friend. But, if the only friends that the person has are other friends with disabilities, like many of the people I work with through People First, nobody has a car. They like me. I am really a good friend. I have a van that drives people home at two o'clock in the morning if they want to stay late at parties. For many of those people, I am their only friend without a disability. They need more friends like me in each of their networks. So there's nothing wrong with having friends with disabilities, but there are limitations if that's all the friends you have. Some of the things that we mean by inclusion are not going to be able to happen as easily. If you and your four friends go to the Y, swimming, and all four of you are in wheelchairs, that is going to be a big event at the Y. When four people in wheelchairs showing up together, it's going to be harder for inclusion to happen. Whereas if one person in a wheelchair goes, to the Y, becomes a member, and goes there every second day, they have their locker beside a woman, and eventually she starts to talk to the person. They're going to start a connection going.



All of us have many acquaintances. If you and I were to count acquaintances, from all of our settings, we have thousands. But

acquaintances aren't good enough. We have to try to get more of those closer, more intimate kinds of relationships. For some vulnerable persons, all the people in their lives are people farther out from the centre of the circle. So there's been a lot of thought going into trying to figure out how to do that.

First, we have to know and believe that people with disabilities can have that inner circle of friends. Twenty or thirty years ago, when we talked about integration we didn't think it was possible--we didn't even think about it. Now we have to think about it, and we have to recognize that all persons can have close friends, because we know lots of people with very severe disabilities who do have very close friends. So it can happen.

Approaches to Making Relationships/Friendships

Let's look at some of the different approaches that have been used. There are different approaches and different names for things, but we're going to look at four--bridging, social networks, circles, and leisure identities.

Before we start, I'll just name another that's not on there, and we'll just see if anybody else has had this. Has anybody built, tried to strengthen the social networks of somebody you know, a family member, or a friend, through what we would call a one-to-one program? In other words, where a one-to-one match happens. Big Brothers, Big Sisters are perfect examples of a one-to-one program. High school, they had a one-to-one, so that it was around academics or social? Peer tutoring? High school students can actually get a credit for being a peer tutor, so that's a one-to-one. Best Buddies. Respite is often one-to-one. SSAH workers, another one-to-one. .

One of the reasons why we've come up with this new list, is that we've found often, with one-to-one programs, that the person doesn't develop close friendships at all. If a student does it for a contract at high school, it may not lead to a real friendship. It may actually block real friendship from occurring. But even if a friendship does occur, oftentimes those only lead to one relationship. We had a match for our daughter through Extend-a-Family. It was a family-to-family match, but that would still be an example of a one-to-one. We and my daughter have been involved with their family since she was four years old. She's in her mid twenties now. She has met very few friends of theirs, she has met their families, she'll go off to them to Burlington to see grandma and grandpa, she's met them, but not their friends, not one single one of their friends. Why? We have to look at this situation and its limits. We would not put this down, because this is obviously a lifelong friendship for her. There are two girls, two young women who are very close to my daughter's age, so it's been great over the years. They're very, very close friends. They'll be at her circle meeting on Sunday. But the problem which we didn't know is that the children were homeschooled. This was very limiting in terms of their relationships and friends; they hardly have any friends themselves. In fact, Karen has connected them to her friends. Sometimes they stay connected. One of them ran into one of Karen's other friends at university, and now they are good friends. That wouldn't have happened without Karen, but it's not supposed to work that way. It's supposed to work the other way. The person with the disability is supposed to have access to their networks.

So let's see how some of these other approaches are a little more conducive to building more than one friendship in that inner circle of closer friends.

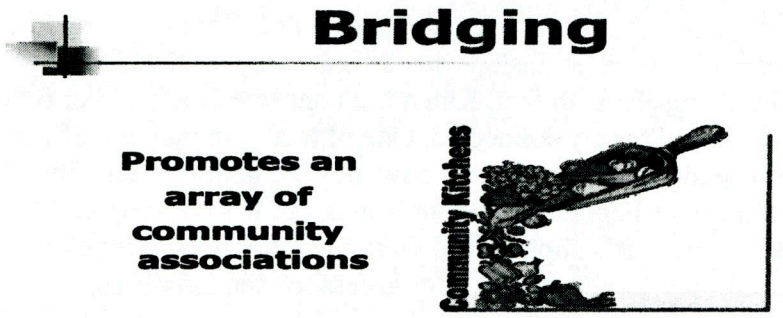
1. Bridging

The person who really made us aware of this concept was John McKnight. He uses the word associational life for the informal organizations in our communities that may be more conducive to bridging than big, formal services.

Let's discuss some examples to figure out what that means. An informal group is what we call grassroots, people just coming together. We start with two, and sometimes the two grows to three. An example of an informal association might be a community

garden. Maybe you get to know the person whose garden is right closer to yours a bit better, which is great, and a watering can.

Parks and Recreation activities are another example. Let's look at them from the point of view of inclusion. As parents, we have to drive our people there and probably have to get away afterwards. Your family member could be really disappointed at the last minute when a program is cancelled due to low registration. So there are issues. Is skill development the most important thing, or is relationship development also very important? And if so, how can we bring the two together? Can we not have some more informal kinds of leisure that achieve both?



There's another concept too. Does anybody have an example where being involved in one of these associational kinds of experiences has actually led to an employment opportunity for somebody? So this can often happen, somebody can have an interest in somebody. Let's say somebody you know is interested in let's say in radios, so they get really into that, and get part of a radio club, and then, eventually, if they're connected through more informal ways to other people, who have those connections, that could eventually lead to a job. It might initially be volunteer work, and then sometimes the volunteer work turns to paid work. So it's a process.

With bridging strategies, you have to build on the person's contributions and gifts. We can't just identify people's weaknesses. So community associations are interested in people's gifts. We had a big advocacy thing on our street, where the city was trying to cut down trees, and we needed to get neighbourhood help. We didn't go around door to door asking each person what their weaknesses were, and how we could fix those. We said, what's your skill? They said: I can type, and I've got a photocopier at work, I can do free copies, I am a lawyer. So we asked everybody their gifts. That's what community does. It's not that we don't all have deficits, but right now we just need to know that you can type a flyer that we're going to run off 500 copies to send around the neighbourhood .

Find settings that are welcoming and hospitable. If they're not, if we can't do some work to make them more hospitable, then we move on, let it go.

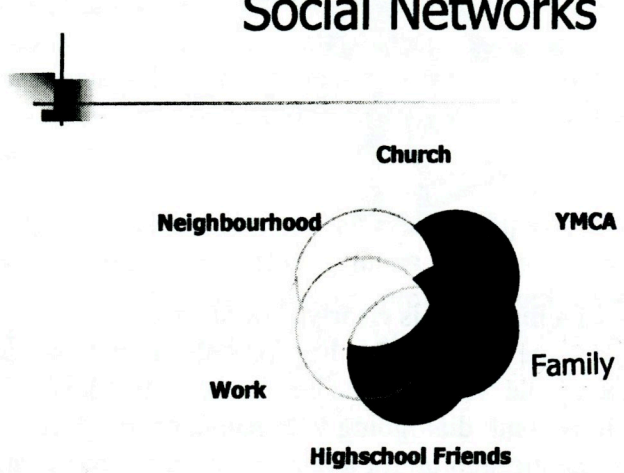
Find natural connectors. Rather than always relying on paid people for things, we see more natural connectors. For example, my daughter loves the church choir, and has been in it for years. There was one woman there who really seemed to show an interest in Karen, and so we actually spoke to her and worked with her, a few years ago. She then took on the job of connecting Karen to the rest of the choir. That's a natural connector, we didn't hire her. She was there already, she knew everybody, she had the connections.

Are some people better suited to be bridgers? Can parents be good bridgers? Well, tired bridgers. So maybe we're not the best bridgers, but if we have good connections, and are a bit extrovert, we might be able to make some connections. But we need to find others. So who are good connectors? Peers. That's a good example.

2. Social Networks

The second approach is often called social networks. One way people often use the social network approach is by having a planning meeting (sometimes a circle, but not necessarily). They draw the different circles in the person's life. Not everybody is going to have church on their picture. They individuals' names are put on the

appropriate place. You might say, let's pick the person from church in the example of my daughter I just mentioned. So we'll put her in church, and we might also consider whether she is a close friend or just an acquaintance and figure out a code for noting this on our map. By doing this, you are able to figure out how strong the person's network is. If all the close people you put on there are other people with disabilities, you're going to say 'how can we change that'?

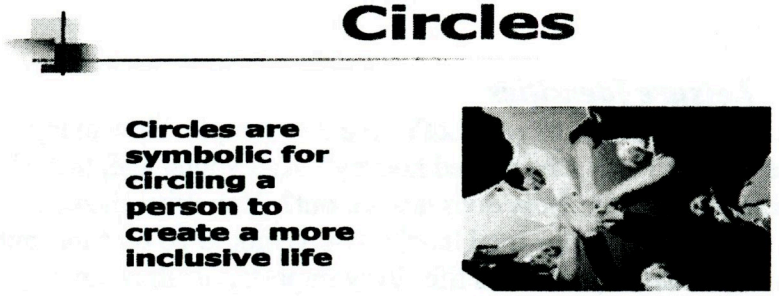


Let's say there's somebody in the neighbourhood, and they're an acquaintance. Let's say, every single day, your son or daughter talks to that person, they're on very friendly terms with them. It's quite good, it could be better. Well, rather than starting from scratch, and going to some agency and getting some one-to-one program, start with that relationship and try to strengthen it. So that's one of the principles: you make use of what's already there, and see if you can strengthen that. The nice thing about this approach is we're not just talking about building one friend. We're saying we've got all these different environments, and there should be expectations that we can have friends. The picture, in this way, is much richer in possibilities. It's not one circle, it's five or six circles, so potential for friendship there is very strong.

So this is the way you put it into action. First, you draw those circles. Then you ask what friends exist, what potential friends might exist? How can existing ones be expanded, or maximized? This is better than starting something from scratch, like a circle, where you're going to do everything, getting all new people. Why would we do that, if we've already got things there in place that can just be improved? Borrowing somebody else's network is awesome. That's essentially what happened when my daughter got to borrow Ruth's circle of friends in the choir, and now that circle is one of her networks. We all know that, it just happens, but we often haven't thought about applying that to people with disabilities.

3. Circles

The next approach is circles. How many people here have been involved in a circle?



A circle is a symbol of your intention that everybody comes together around the person, for her/him have a more inclusive life. That's all a circle means. It may be either a friendship circle or a support circle, or a combination of the two, as my daughter's is. Sometimes a circle may have one aspect or the other at different times. At high school, it was more friendship; they were not providing that much support.

Or planning can occur with circles, as we have this Sunday for our

daughter's circle. Sometimes they coordinate things. A member of the circle may be going to make sure that something is going to happen over the next several months. They take on different functions. That's the nice thing about a circle, it's whatever the group wants it to become. And, of course, it's got to be grounded in the values of the person.

4. Leisure Identities

This idea may be new to you. Let's give an example. How many people here had kids who played hockey? At a young age, they show an interest in hockey. How does it work out? You drive them, you pay a lot of money, it's a total hassle, you've got to go on trips, but this is important to your kid's life. Very important is they develop an identity around this. You decided that it was worth this hassle and finance. Their identity is strengthened through being involved in that leisure activity.

What happens with people with disabilities is that they often do show a leisure interest, but we don't take it seriously, and we don't promote it to the same way that we would for our other children. So this is a chance to do that, when a person shows interest in some kind of leisure activity. It could be a work interest too. When we take that seriously, eventually friendships should be able to come out of this, because they spend almost a lifetime doing this. My brothers are still playing hockey, and they have friends they made in hockey; they've stayed involved. Their interest has changed, it's not competitive like it was, now it is more leisure. So leisure identities can be lifelong. So how do we take it seriously for people with disabilities?

Leisure Identities

Here's an example of a man who is clearly now at a more competitive level. If some people in his life--parents or friends--had not taken him seriously, he would not be here today at this level. Several things are important: dialoguing with someone to figure out interests; helping someone sign up for a recreation program; assisting someone to buy proper equipment for an activity they love; linking the person with others with similar interests and expertise e.g., mentoring; and creating the conditions for person to extend their interest and identity. The strategies are similar and important for an employment identity. And these connections lead to friendships.

Conclusion

Which of those four types of friendship building is the best method? We can even add one-to-one. With my daughter, we don't only have a circle, we've got all those other things going at different times. Right in the circle meeting, we bring in the social network. I think when we come up with any one thing, and think that that's going to

solve all our problems, then probably we're putting too many limitations on things. If my daughter only had a peer circle, her life would not be very rich right now.

You might say, we do something else. That's great. We need to know about them, because if you don't know what a circle is, what its potential strengths and weaknesses are, and what you can do to make sure that the weaknesses are kept down to a minimum, then we can't improve things. We're not going to have more inclusive communities, because we have to have strategies to do this, we can't just have wishful thinking. Wishful thinking does not get inclusion. We have to have concrete strategies. We have to be knowledgeable about each of them, and figure out what's the best in our personal situation.

I think the bottom line is that relationships are the most important. My daughter's Tim Horton job is working out because she's made so many great friends. There are problems, but it's working out well because of friendships. The Tim Horton's boss is fantastic, too, that has made a difference. The minute he walked in the door, he had high expectations. He connects her.

Leisure opportunities, signing her up and sending her off to karate, often did not bring too many relationships. Sometimes she chooses to do karate, and that's fine. If we could figure out a way to do make more of karate, then good. Now she's doing tai chi. She went downtown, walked into this tai chi place and signed up for it. Then she went the first night and there was somebody she knew there, a friend of ours. Well, now every week, after tai chi, they go for coffee right next door, and they've now become friends. Because Joy knows her well, she is able to connect Karen with other people at the class.

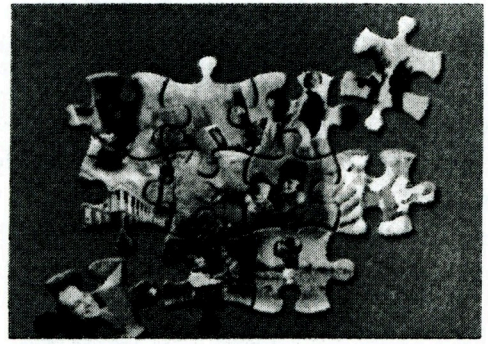
Regardless of the approach chosen, it is important to be able to ask people to get more involved. If we hadn't asked the person in the choir to take a bigger role in Karen's life, nothing would have happened, Karen would still just be going every single week, being friendly with everyone, but not getting deeper, not getting to the three or four close friends that she now bakes and does dinner with.

In summary, I'd say that relationships are key to meaningful work and recreation experiences.

To end, let's look at several pictures of leisure activities, this time with a critical perspective (see next page). These pictures of typical recreation programs may be good for co-operation, fitness and, skill development, but perhaps not for forming friendships. Which are and which ones are not?

This is not such a complicated puzzle—

to make inclusion happen



How Families and Communities Can Make Creative Options Work: The Windsor-Essex Experience

Workshop by
Marlyn Shervill, Alice Quinlan and Michelle Friesen

Marlyn Shervill:
We decided to begin by sharing some of our history--fifteen years' worth of work in Windsor and Essex County. Some of what we're talking about didn't just happen yesterday. And it was a real community effort--meaning people and families and service providers and community people. When the Ministry brought out Making Services Work for People in 1997, lots of different things happened in various communities. In Windsor and Essex County, we decided that we were going to make services work for people. That was the goal. We decided that we were going to build tomorrow on what we were doing today. So that's how we created the Windsor-Essex Brokerage for Personal Supports. When you look at the overheads, this is our language in Windsor and Essex County. Every community has its own language, but this is ours.

Some of you may have known Malcolm Jeffreys, who used to be the executive director of Community Living Windsor, and sadly is not here anymore. He really did a lot of leading in our community, in terms of agency transformation.

In the traditional service system, under one roof, the responsibilities of the agency included advocacy, planning, and the design and delivery of the service. The agency received the money from the Ministry and the agency allocated the dollars.

We decided that we were going to begin to move to an empowerment model. And we were going to separate out advocacy from service delivery. Separate out the planning from service delivery, and separate out the money. The agencies wanted to be great service providers" "Tell us what you want, and we'll figure out how to implement it." That was their job. The advocacy was separate, outside of the service delivery—with Family Network, People First, and a seniors' family group called Family and Friends, which is also an advocacy group. And then we have paid advocates, APSWs, and citizen advocacy in our community.

Planning is unencumbered. We used "unencumbered" because, as you will see, the Ministry decided to fund brokerage. There's a whole question of what's independent and what's unencumbered. We call ourselves unencumbered, because the money is still coming from the Ministry of Community and Social Services. The Ministry allocates the money, and at this point, it is attached to people. And then folks figure out what it is that they want to do.

It seemed to us that the traditional model in agency planning was based on the assumptions of a fear of failure of benevolent care--"just in case". We wanted to move it to "just in time." So, we ask: "What do you need today? Figure out what you want to be doing today, and what does that look like?" This is different from the "just in case" assumption, which says "just in case" something happens, I should be asking for everything that I'm going to need for the next twenty years. We wanted to move from a "just in case" to a "just in time" approach to allocation and planning.

The traditional model of social services is derived from old social policies from ages ago, based on veterans's administration and our institutional system. We decided to move to an empowerment model in which people figured out what they wanted. It automatically presumes the rights of people and that they can determine their lives, with the support of the people that they trust.

The traditional model led to over-design, over-service and over-cost, and made people more dependent. The agencies were choosing who they would support, and there was a lot of dependency. This encouraged waiting lists. People were called clients or cases. We wanted to move to creativity, individual choice and control. We wanted to resist the organization of agencies as service monopolies. We wanted to create competition, so wherever a person or family wanted to purchase services, we would figure it out.

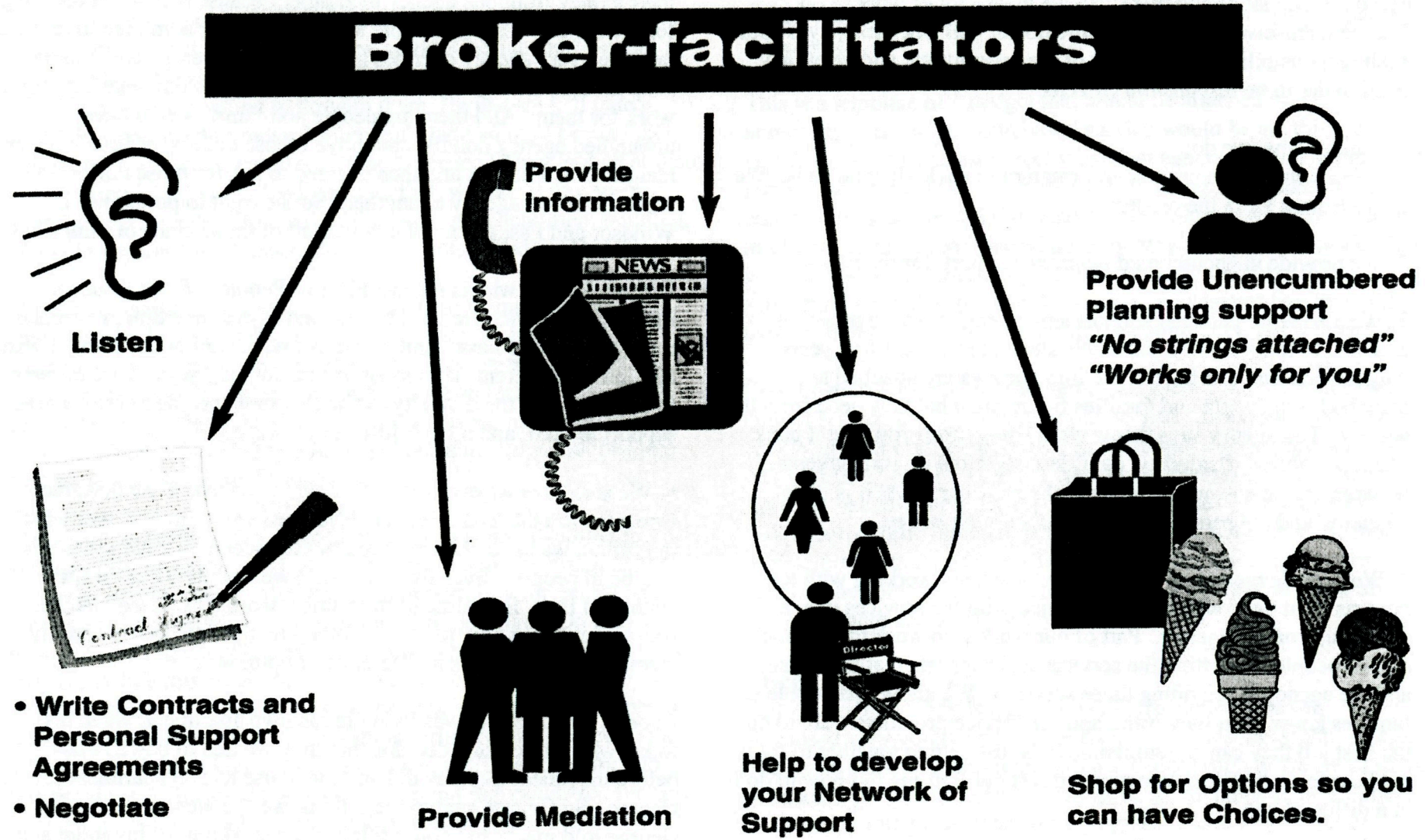
Lots of folks were saying to us" "We don't want a support worker at work." So stipends were paid to employees who were also working—as in John Lord's example of two women workers who were both Bell employees. People felt very content with being supported by a fellow colleague or a fellow employee, as opposed to having a support worker. We wanted to encourage participation in the community from an array of opportunities that we all have.

Developing the insights of People First of Windsor, we moved to the idea and language of "person-directed" planning. We don't use "person-centred" in Windsor and Essex County: that sounds as though vulnerable persons are still in the centre of something, that people are still talking about them and not necessarily including them. So the People First group moved to "person-directed". They are in the director's chair. Soon Alice will tell you the story of how her son Isaac began directing his life.

Another recent example. A mother called to say, "I think my son Sean is going to have to move out. We can't handle it anymore. My younger son's life is falling apart and I don't know what to do. I want you to facilitate some way of planning how Sean moves out. It may be a group home. You know I've done everything about being included, but I'm done." So I went over to their house. As we started chatting about Sean moving out, Sean began to pace, and pace, and upped the pace. I thought the banister on their stairs was going to come off, he was just so ticked. Next morning I was facilitating a meeting with the agency, family, Sean and friends, and Family Network. I said, "I can't, I'm not going to stand here and talk about Sean moving out. I'm here to facilitate something that's going to talk about options. Clearly Sean does not want to move out from his family." Sean's parents then started to talk about renovating the basement, Sean having his own space, and how to make that space safe. In the middle of the facilitation, Sean got up, came up to me, stood in front of me, gave me a great big hug, smiled, and went back and sat down, and we finished the rest of it. So I knew we were on the right track. To me, that is what the person-directed stuff is about. When everybody left the room, including Sean, we all had responsibilities, and Sean knew that what was happening. But then I got another phone call. Sean's mother was really struggling again. She said, "The room is ready. We planned to make this transition really slow, because that is how things have worked best for Sean. But he's pacing again, he's up all night. It's a tough time again." So we said, "What about moving now?" Stuff started to go from his bedroom to downstairs, he's got a smile from ear to ear, and the next thing we know, he's sleeping eight hours. Now we know that this is what he wants. He has figured out how to tell his folks clearly, "I'm ticked." We learn that we need to listen differently.

One of the pieces of facilitation is about networks of support—what other groups and communities may call circles of friends. We don't use circles in Windsor and Essex County, because our People First members say clearly "We don't want to be in the centre of anything, we want to be part of something." So that's why it's networks of support in Windsor and Essex County. Folks themselves will say that a network is about family, friends and other people in their lives. Part of the work that Brokerage does is assisting folks to create their networks.

Another value is about being part of the community. I guess some of our fears are incredible for folks, just incredible. We all know that people have been chastised and called lots of things, and been quite abused in our communities. As People First members tell us, there is so much work to be done in our community, especially with our students, and our other high school students on the buses in Windsor and Essex County, for example, that won't move their book bags to



"Facilitation of Personal Supports" -- The broker-facilitator works only for YOU!

Diagram first developed by self-advocates and People First of Windsor members - Windsor-Essex Community Planning 2000
Available at Windsor-Essex Brokerage for Personal Supports - Updated April 2005

let somebody sit beside them. So we have a lot of work to do. People themselves, People First members, will talk themselves about their responsibility in being part of the community, and what they need to do, to be responsible citizens.

So, this is what we do:
1. We listen and we provide information to anybody who calls. We get to learn a lot in the process.

2. We provide unencumbered planning support, for the person.

3. We also write personal support agreements, because money is attached to folks in our area, and has been for the last five years. Any new dollars that have come into our area are attached to somebody, so people and families figure out what they need from the agency. The agency says this is what I need from you, and it talks about portability, flexibility, confidentiality, but it is an agreement between the person and family and the provider. And it is done annually, and the person and the family set the budget.

4. We provide mediation. I think we have been working with ten persons right now, who are not satisfied with the services they are receiving from an agency. Part of our work is to work that through, so that people are getting the services and supports that they want, and the agency is providing those services. We know that people and families know what they want, and the service providers want to do the best job they can. So sometimes it's just getting together to figure out how to do that, and sometimes it's about figuring out how to do it in a different way.

5. In Windsor-Essex, everybody has a right to portability. The Ministry of Community and Social Services and every agency's service contract with the Ministry says that people and families can move their money from one agency to another, if they so choose. So there have been people who have moved out of our community, and have taken those dollars with them, to be able to buy services and supports in another city. There have been people that have moved their money from one agency to another because they got more bang for their buck. They were able to negotiate their administrative costs, because every agency operates just a little differently, and people shop around and figure that out. And they figure out what's going to work for them. And there are people and families who have unbundled agency dollars, and moved those dollars, or first had them identified in a budget and then decided to ask for those dollars to move from one agency to another. So the right to portability in Windsor and Essex County involves all of those kinds of things.

Richard Ruston who is the president of People First of Windsor likens choice to ice cream flavours, and says at one time, it seemed we always had to have vanilla. I don't want vanilla anymore. I want all kinds of different flavours of ice cream and I want those options. In order to have the diversity of life that most people have, we need support to do it, and it can't just be one way.

6. We also have ways of discussing what happens if we disagree. One situation that can arise is a difference with families over what's the person wants to choose. We absolutely believe in families who will be in people's lives forever, while we're only there for little chunks of time. But some of the hardest work that we do is to help people figure out how to say what they really want to their family members when there is a difference of opinion.

George, for example, was living in his own apartment, when his folks, who are seniors, decided that they wanted to buy a house before they died. So they did and the house had an apartment for George. So George said to me, I think we'd better go for dinner. George told me, "This house thing is not working for my mom and dad. And it's not working for me." So I asked George what he thought he needed to do? He replied, "I think we need to move back into an apartment building, and they need their own apartment, and I need mine." I asked him when and how he wanted to talk to them about that? George said, "Not now. Dad's just hurt his shoulder, and this is not the time." So we discussed how and when to tell his parents. About six months went by, before he said "It's now.

Winter's coming, it's now." George said, "Marlyn, I want to do it at that meeting… I'll tell them, but you sit right beside me." So that's what we did. He said, "Mom and Dad, this apartment, I hate it." He didn't say it had anything to do with them. He just said, "I hate it, and I think we need to move." Mom and Dad had only been in their house, for about eight months." What happened? They looked at their son, and said, "Oh thank God you said that, we hate it too, we're putting it up for sale!" And so they're back in an apartment building, living in separate apartments. And life is quite good for George.

[In reply to audience question] It's really interesting that you ask that, because I was part of a meeting yesterday when the key question is how do we ensure people's dollars are attached to them, while recognizing that agencies needs infrastructure dollars. We'll have those identified on the budget as well, as we may need to look at how infrastructure dollars start to get portable down the road, so that somebody is not stuck somewhere.

It is very complicated, but what I can tell you is that planning for one person at a time has worked. It's not without a ton of struggles. But if you go in with the idea that this is an opportunity for everybody that's living together to really take a look at their lives. Do they want to stay living together? Do they want some changes in their life? Do they really like this neighbourhood, and is this neighbourhood really terrific to them? So if all of that can be looked at, then lots of people want to change their lives. So it's an opportunity, as opposed to the attitude of: "I don't know if it can be done, until there is policy in this province." But we do need policy around individualized funding in Ontario. Without policy, people and families are at the mercy of the agencies, to keep their budgets separate. Our safeguard is that the Ministry keeps a list of everybody and what they've got.

We have a template type of agreement. People and families add in anything and everything that they need to. The agencies will add in their monitoring and quality assurance stuff, that the Ministry says they are responsible to do, in conjunction with the people and families. But because the money runs through the transfer payment agency, until there is policy change, we're still holding the agency responsible.

This is a template of a budget that would be attached to the agreement. An agency-purchased service would be anything that you're going to purchase directly from an agency. The community-purchased service is anything that you're going to purchase from the community, whether it's a stipend to an employer, whatever that might be. Lots of people need transportation to and from work. Now we just label it as community involvement, for the folks that are supporting as well as the people, because you cannot live on what they're living on, and have a life in the community, it's impossible.

Coordination fees may be charged by an agency that provides that kind of service for people and families. But some people in families are hiring their own support people. Families can also hire somebody that's working just for them, to coordinate everything. And that's working, because there are no other vested kinds of interests except that person coordinating supports and working with the independent contractors, or the supporters with that person, and helping open doors in the community. So the coordinator fees would cover all that. And there are administrative costs.

Alice Quinlan:

Hello everybody. My Isaac, who is 29, has autism. He was diagnosed very young and, at age five, he also lost his sight. At age five, Isaac started attending programs--every program we could think of, feeding programs, behaviour programs, you name it, he's done it. I don't even like to hear the word program. Isaac was very, very self-abusive, forever beating his head. From about age five to twenty-three, Isaac had to wear a helmet to protect his head. He was non-verbal. He would never sleep; we'd be up for three nights at a time. We went through a lot of rough times with Isaac. I never thought things were going to get better.

At age twenty-one, Isaac was no longer able to attend school. So we had him home for two years. Well, we had a crisis. I couldn't even

get doctors to help me with Isaac. He had black eyes, he had split lips. He had a hole in the side of his face, right down to the cheekbone, from the self-abuse. He was so strong, we couldn't even keep the helmet on him to protect him. That was a really, really hard time where I thought, "I can't handle this anymore, I don't want to see my son suffer any more." I almost made a very bad decision. I almost ended my son's life, with me. But I got some emergency dollars. Isaac attended yet another program, but it wasn't working. He was still up all night, and screaming. He wasn't happy in the program. It wasn't helping him. Every day, he'd say "No go to school, no go to school, no go to school." He would be up all night, and then I would have to get him up early in the morning, get him to school for eight-thirty, and pick him up at three-thirty. It was meant as a kind of break for me, but it wasn't a break, and it wasn't helping him at all.

So Isaac eventually got some individualized funding. I went to that agency and said, "I'm taking him out of school." There were a lot of hard feelings there. We didn't want Isaac to start until ten-thirty in the morning. And the agency said, absolutely not. He's here at eight-thirty or you're going to have to pay from eight-thirty to ten-thirty. What a waste of money! So we decided to take him out. Brokerage helped me, they came into my life, and when I got the individualized funding for my son, we started doing some planning. We thought: what about hiring a support worker? I was nervous. We started putting up ads, and looking for support workers for him. Don't forget, my son always had a helmet on, and every time he walked his arms were full. He could not walk all these years without arms full of objects, because if he let them go, then the abusiveness started. So he had to have them, he would even walk with a beach ball between his legs, as a form of self-restraint to prevent him from banging his legs together. This was how self-abusive he was.

I knew Isaac was smart, but I never thought that he would be where he is today. Now he is twenty-nine years old. No helmet. He doesn't have to carry anything in his hands. And he's happy. He actually has a smile; he's always got a smile. When we interviewed possible support workers, Isaac was involved. With the first two, he would come in the kitchen and disappear. He would hear them talking, then he would disappear. With the third support worker, he pulled up a chair, he sat beside her, he felt her face, she didn't cringe, she wasn't afraid. I thought to myself, my God, he actually understands, and he can feel the comfort from her. He has a sense that he could trust this girl. Well we hired her. What is so nice about doing the planning for your son or daughter, is that he can actually make choices for himself. I don't have to do all the planning, I don't have to do all the choices. So Isaac and I plan out his day. If I want the support worker to work five hours a day, I pick the time that's going to work for me and my son. Not that's going to work for the worker.

He has got such a wonderful and full life today. To me it's a miracle. I never, ever, ever thought in a million years that this could happen. Isaac has got customers that he shops for, he goes grocery shopping three times a week for them, with the help of the support worker, mind you. He tells me what he wants for dinner. He speaks in sentences; he never did this before. He was very non-verbal, a few words at a time. I just can't believe the transition that took place in him, with the choices. And planning has made such a big difference. I just wanted to share this with you, because if you have children, and you have funding, you plan for your son or daughter, and you're going to see a world of difference.

Michelle Friesen:
I am with Windsor-Essex Family Network, an autonomous family network in Windsor and Essex County. Alice is a member too, and Alice and I find a lot of mutual support in each other. We have had many similar challenges with our children, both are not sleepers, both of us have had experiences where we thought we can't do it any

more, and want to end it. Both of us have, both we hope inspired other families. We both are part of a smaller group within our network, that we call Gathering Around the Hearth, or Gathering Round the Hearth, that came together a few years ago, when it looked like Brokerage was under threat. When the government changed and started to put more pressure from Queen's Park on these local creative initiatives, it was looking like Brokerage was going to take a hit, and be axed. And so our fear of that, as things rolled back, meant that a number of families gathered together, to say, we have had some good experiences with this, let's document, let's talk about what's working, let's put a brief together, let's say what we definitely don't want to see change, let's get it to the Ministry, and see if we can, at least, get them to stop rolling back, if they're not going to enhance it. And Alice was part of that group of families, and I can honestly say that we were successful, by educating how much it was helping people, and by bringing forward those stories of Isaac and others, So the Government put the brakes on their plans. That was maybe four years ago, so we're thrilled. You need to know that the smallest things can be so significant four years later. Now people from around the province are noticing that there is planning and facilitation support that is funded by the Ministry, and is completely independent of direct service agencies, even if it is the only one.

When I think back, if we hadn't taken the time to step up, and put some energy into that, who knows if we'd be here today talking to you about this. And the other thing, as a young mom reminded me, we had a few families that actually went the day that the agencies were going to be told about the changes to the Ministry office. Integration Action, these young families who knew, that if we don't have this when our kids are older, what are the chances of our kids being included in community? They just banded around that doorway, as the agencies and the Ministry went into the room, saying "We don't want Brokerage axed." Sean, the same man that Marlyn talked about, had a meeting. He had been not accepted by the school system, and his family was struggling. But Brokerage was trying to help them try to do something while he was home all day long, at a very young age. He walked in and asked to speak to the manager at the time. He had a sign, and he can read very slowly, he has autism, and he said something like "please don't shut Brokerage down." So don't ever underestimate the things that you can do in your community. Because if things aren't in place as you want to move forward, there are some things you can do. We need to start moving in some of those pieces, in our communities.

We are a network of parents, brothers, sisters, and friends who have come together to promote the inclusion and well-being of our family members. We do that by sharing information, and by offering moral and practical support. Our mission is to empower individuals and their families, affected by disability, and to enhance their quality of life through information, learning opportunities, mentoring, and community connections.

We really believe in the value of each family's wisdom, and their knowledge, and we are committed to full inclusion. That doesn't mean that, there are people that are at different points along the way. We believe that every family must be respected, and the person in that family valued and supported to be in community. That everybody has gifts to contribute, the right to full citizenship, and the value of each person's individual right to make choices.

We had been an informal network since 1995, but incorporated a couple of years ago. I'm excited about the mission statement and the values and beliefs that our Board of Directors, through strategic planning, has set in place. Everything we do goes back to those values.

What is most successful is the linking and mentoring. We have a family-to-family project, funded through Trillium, to expand more one-on-one mentors. We are constantly providing information and offering workshops. We work to create systemic change on committees and boards, and to be a collective voice. One other thing that has been helpful, and that you find in a lot of family networks, is

the creation of innovative and practical resources for families.

The mother who runs the Chatham Family Network has written a fabulous book on helping people with support workers, and the individual stuff that you might do. I've brought a couple of them, to sell today. We've developed a training series and manual, for folks in transition, from teens from high school, it's called Networking for Success in Our Community. Other communities have adapted it. Hamilton's is called Future Directions. And this is a series of workshops that families will participate in, with their son or daughter, as they talk about what is their vision for the future. In the sample manual downstairs, there are good examples of people's visions, in visuals, with images.

One of our parents researched and developed a planning folder kit, called My Future Unfolds. It hits on six very important areas, many things that we kind of keep putting off planning, as families. How to take care of yourself to be a good support; how the person can be the best they can be. Topics include kinds of home and community; contributions and participation--how to participate in your community, how to be strong and supportive; it talks about the financial stuff. So every folder has a different topic with checklists, so you can ask yourselves, "Have I done this yet? OK, I'd better look into that. Where are we at with our will? Have we taken care of some of our financial stuff? Maybe we should be looking at what kind of a home." We've brought many of these, they are ten dollars apiece. It includes a holder, so that you can work on one thing at a time, stick it in the folder. When you feel like it again, do it again. So some of powerful things that come out of the networks around the province, are resource materials, the training sessions, the creative stuff that families come up with. Probably some of you in this room, in twos and threes, could have great ideas, and could be putting them together.

One of our parents who started the Windsor Family Network, Alison Ouellette, has written a book about her son. These are on display, and for sale, at the ASPIRE table. The willingness of parents to share their success stories and their creativity with others is another way that people are strengthened.

People feel that this is a workshop for us to really look at our gifts and our strengths. Families tell us that the daily work and the battling of those systems builds up huge stress levels. Calling the Family Network or meeting someone else helps. What we're finding is the younger families are struggling so much with the education system, it is so important that there are people there to build them up. By the time they have adult children, they may be too crushed to be creative. But we also know how resilient we are.

Resilience is the power of recovery, it is the ability to recover, to spring back, to original form from change and adversity, which bends, compresses, and stretches you out of shape. High level resiliency is the ability to spring back stronger and farther ahead. And families are very resilient!

So if you're here, as a family, you know that, you know you've been really low, and you've been resilient. If you're here because you support families and individuals, that those times when they look really, really low, doesn't mean it's over. No, it means that there are strengths and gifts to draw from, and that families will bounce back, and we just need, that person beside us to say. "Wwhat does it take? What do you need now?" And do it.

There are a couple of stories that I wanted to share, about families understanding the importance of autonomous planning. There was a mother I worked with on the restructuring in our community, when we were doing the things that Marlyn talked about, that started in 1997. She was a senior mom, and very frail. She was part of that restructuring table, and we got to know each other well, and she talked to me about her son, who, in his thirties, said, "Mom, I want to move out." So at that time she looked for something for him. That was in the early nineties, I think. His first place didn't work, and

they moved on to something else. This was a mom in her seventies, who thought, boy the system really needs something to help empower people, something that works for them. She started volunteering on the Brokerage project, and stayed on the Board until it was stable, about a year or so ago. Because she could see how important this would be for the next generation. Her son was in traditional supports, by her choice, yet she really knew what younger people were going to need. At some point, her son was calling home, struggling with things that were going on in his apartment, he had a roommate, and there was support coming in and out. She would say, we had a meeting, and we told them this, and we told them that. Finally, we asked, "Do you need a bit of help Frances? It doesn't seem like they're listening to you. You've been telling me this for over a year." So we talked about Brokerage coming in, and doing some mediation. And what about a couple of us coming in to take notes, to stand beside you and the other family? And she thought that the timing was right for that. When I talked to her the other day, to say I'd love to share their story, she said "Good." In her mind, she was waiting for the right time. She was watching how solid Brokerage was getting, she was watching to see if people were going to take portability seriously, she was watching for the right time to come in and ask for the mediation help. And felt the timing was right.

So Brokerage went in, as an agent for Donald and his roommate, to mediate, and Family Network went in, to help back up the voice of the families, and take notes. Part of that process meant that Frances, my friend, who was the senior mom, had to educate her son's roommate's family, who happened to be sisters, as the parents were dead. So the sisters were taught about various things in the community that could help, there were a couple of family groups, there was Brokerage, and they were very interested. And then that turned into us mentoring the sisters, about the system, where to write a letter, where to send the letter, what you could say? So the sisters turned to Frances and said, "We want you to know that we will always be there for your son." She'd been starting to get very worried, and we saw her shoulders come down.

Through the meetings of this network of support, some friends from Family Network, these new-found friends and this family, the support changed. This mom was very clear: "I don't want to take my money out. I just want them to know I can. I just want to talk about how to make the supports more individualized for my son and his roommate." And the family was interested in that too. That agency has worked with the families and did a complete 180-degree turn. The supports are the way both families wants. And Frances knows that her roommate's sisters will always have an eye on her son, when she passes on, and they will be his network of support.

None of this could have happened in another community, where there wasn't the unencumbered planning, there wasn't the commitment to portability, and there were not some autonomous family groups who were educated to help.

So we need to keep in mind that it's not always about the new money, and the very creative strategies, and the younger families doing them. It's sometimes about the champions that are right under our noses, who may be using traditional supports, but see a bigger picture.

One of the chairpersons of Family Network, who led the restructuring, earlier chose a group home for her daughter, out of desperation and as she did not have the options in place. However, she continued to fight two more years, as the chair, to make sure that we would have the model in place that would prevent that happening for other people. There could very well be champions in your community, who would just know from their experience why something should be changed.

Another example in our community. People really thought this person would never be able to live in the community; she had some significant mental health disorders as well as intellectual disabilities. She had been institutionalized for her teen years, at a treatment centre, and got individualized funding when she turned 18. In those

days, the planning questions were: What next? Where will she live? There were various stages of trying her own home and not being ready and going back to the treatment centre, and then having her own home and that not working, with a roommate and twenty-four hour supports, and sometimes two people to two, and still not working. She ended up having to go to the hospital, for a 5-6 month stay.

We started to get together as a network of support around what to do. We knew this was temporary, we knew there was med stuff, but that she couldn't go back to 24-hour support in a group home setting. If didn't work, even if they own their own home. The family took a while to sort through the planning, and decided they really knew their daughter, and that they needed to be closer, so should probably build an apartment in their home. If they converted the garage into an apartment, then they could be close by, and provide support. So we had our first meeting at their home in the garage, with all kinds of junk around us. When they said they were going to turn this into an apartment, the two agencies that were supposed to help were not keen.

So we got Brokerage there to negotiate and facilitate, as an agent for the person, and some friends and family. The sister was there, and I was there, and another mom. The family was trying so hard to say, we think we need to try this. They were vulnerable; it had been a horrible year, their daughter was in the emergency every week. The agency had an idea that she could be in a home, out in the county, so that nobody could get hurt; she couldn't throw things at trucks driving by. This is not the vision the family had. While the agency said the family could "visit any time they want," they happen to have a son in a wheelchair, with a physical disability, who lives with them. So they can't jump in the car and go visit anytime. This meeting was quite stressful and ended at an impasse, with Dad going out to buy supplies the next day, to build the apartment.

What happened next, I guess, as that the agency knew she'd got individualized funding, and that it's portable. They could choose to work with the family or not. Maybe they really saw the potential. Next meeting, they were saying you could probably run this like SSAH, and hire your own workers. She's been in her own home, in her own apartment, for a year and a half. A very complicated situation. She has help. She likes her space, to be alone now, some of the time, in her bedroom. But she is doing well, though there are ups and downs. We had game plans galore, what if, what if, what if.... She directs her support meetings, she meets with Marlyn, they decide on the topics, they pick pictures to go with the topics, so she knows ahead what the agenda looks like. We talk, and she puts the tough stuff on the table, and so she directs what goes on the agenda for those meetings. And she sits in those meetings. At the beginning it was tough, but she's part of all of every decision in her life. It is amazing, absolutely amazing. Somebody people thought would have to be institutionalized.

So that is another example of Brokerage and Family Network. This mother is a member of Family Network, has been for a long time, part of the Gathering Round the Hearth group, educated, but also needing friends and family to come beside her as her network of support.

Finally, there is my daughter Lisa, who is 24 years old. When she first got out of high school, three years ago, one of her support workers and her daughter were doing Regal. The support worker suggested that Lisa would love to be a Regal representative. "She might like to go in the warehouse, and Anna Pearl and I would like to try it out, take her there and see if she likes it, and sign her up." At the time, her daughter was only eleven or twelve years old. So they set Lisa up as a Regal representative, and there were a lot of people--some neighbours, some friends--quite interested, purchasing from Lisa, putting in their orders, and getting their books. It's an excellent way for her: she goes and we help her, to slide things off the shelf, tick it off the list. We make the list for her. Lisa is very involved, as much as she can be. She knows she can do that. She delivers the catalogs in the neighbourhood, so it's one way for her to get out.

Lisa has several support workers who have been with her a long time, and some former workers have continued to be friends. Julie started kindergarten together with Lisa and went to school with her. Julie was always included to go to the pool, or hang out. My support workers used to call Julie to do things with Lisa, right through to the mid-teens. One day Julie said to me, I'd like to work with Lisa. At first I didn't really want to go from unpaid to paid. It was a bit of a struggle, but then somebody said to me, why can't your daughter have the best? This person has known her since, for ten years, eleven years, she's never been afraid to wipe drool off her face, or offer her a little drink. It was a hard decision, but we made it, and Julie's been working with Lisa for seven years. She started after school when I was home, and then, now she's back in university, she's Lisa's main support worker.

Lorraine's been with Lisa for fourteen years. Another woman started as a support worker and then, as she went into her career, continued to stay involved in Lisa's life. She used to have Lisa to her place once a month on a weekend, to hang out, until she started her family. Now she offers her support as a friend, but also to our backup for vacations, for us to take a break, and for our support staff to take vacations.

Lisa is not coming out of three years of medical problems. So far we've used Brokerage more for picking their brain and for drafting a personal support agreement. We are realizing that we need more and more of the support that Brokerage can offer around creative strategies for support workers, and brainstorming about what she needs, and that planning and including in them in that kind of facilitation.

I hope you've learned from our presentation that there are things that people can do. You can, in your own communities, find the people and places that might have already started a Family Network and get involved. Or look at starting one. Get involved with the autonomous groups that are out there. If there isn't one, start one. I really believe it needs to be completely arm's length, and detached from the agencies. Some of the agencies have offered family-to-family supports as part of their service. I think that's fine, but it's not the same thing, at all, as the autonomous group. Then find people who can do some independent planning on a small scale, and who help each other until we can convince the government that some funding needs to be invested in that. And then find your champions, within the agencies, that want to try creative things.

We just keep asking, we tell the stories. If you're not from Windsor and Essex County, you just develop a plan that says, this is what you need, individualized funding. Special Services At Home is individualized funding, but people who are adults usually need more money, and to know it's there for them. SSAH keeps people on the edge, worrying. It should be core funding, annually, so people don't have to worry. So don't stop asking for it, tell your Ministry office, tell your MPP, send a letter to Ernie Parsons. If you pick up a Family Alliance Newsletter downstairs, the address for Ernie Parsons and Sandra Pupatello is there, and Ernie is interested. If you want that kind of support, he's saying to families, email me.

I am the co-chair of the Individualized Funding Coalition of Ontario. We have a table downstairs. The Individualized Funding Coalition is loaded with material for ideas, and working very hard to help change policy, as is Family Alliance Ontario right now. So, get a Family Alliance newsletter, get Ernie Parsons' email or address, and you just tell him what you're looking for, because they're all ending up on his desk, whoever you address it to. But send a copy to the Ministry as well.

Marlyn Shervill: [responding to a question about how Windsor Essex Brokerage for Personal Supports was started]
It is funded by the Ministry of Community and Social Services. Back in 1997, the Ministry policy was against opening up any new organizations. But our little Windsor Area Office said, no, we want to build it in. And if we build it in, and if we have Ministry money going into it, then guess what, we can get people using it. So, we were a project, first, and then the Ministry gave us annualized

dollars. And we have a Board of Directors, and the Board of Directors is made up of some community people, folks themselves who use Brokerage, and family members who use Brokerage.

It hasn't been worked out completely yet, because there hasn't been enough funding. So the Ministry in Toronto is saying that our pot of money has to support X number of people. So we divvy up that pot of money, so each person or family (like Alice and Isaac) has a budget. It doesn't all get funded yet after five years. But Isaac's three-quarters of the way. So they keep adding.

You're asking how those decisions get made? We have what's called a priority panel; it's the only place in Ontario that doesn't use central access, a coordinated committee with a bunch of agencies. On a priority panel, the people are anonymous--that's the way we wanted it set up. Mainly peers, mainly parents, and we have a coordinator. Anybody's request for support, and this has developed from plans to kind of a big thick form, goes to this panel which reviews everything. And then people are prioritized, because the Ministry is still going for those most in need. There's not enough money, and there are 250 people that have been prioritized for help. What's respectful about it: nobody's life becomes open. Even the priority panel is given only a codename, and the information is not personally identified. Now, of course, in some cases, people are going to guess who it is, as we're not such a big community, but they pick their own codenames. People have really enjoyed picking their codename.

Everything goes through the priority panel--people that are in transition, people putting in a plan for everything in their life, people who want twenty-four hour support. What we try to create, knowing that, is that it would be respectful and private and anonymous. No single agency is making those decisions, all dollars go to the people, and then the people choose the agency they want to flow it through. There are wonderful things about it. What, of course, doesn't look good to people, is that we're not getting any money. For about five years, people have been putting forward requests, but there's been very little funding coming through. However, in the end, if the government is looking for an example of how to allocate, we've come up with a way to look through the plans that's private and respectful.

We've heard of some situations where several executive directors are sitting there and they're all discussing these different situations and cases and negotiating which agency will take which person. That would bring me to tears, if I had to do that with my daughter. I couldn't do it. I had to sit through meetings as the technical support for one of those situations in the early years of the restructuring. It certainly gave me the passion the following year, to ask the parents. It was the parents who created our present way of doing things, and some of the agencies. We had a strategizing committee supporting them, and they really had to fight for it. But I could encourage them by asking: What are the alternatives? And a couple of mothers remarked to Richard Ruston that they were so used to telling their whole lives, that everybody has to live in a fish bowl. And he said: "I wouldn't want that. Maybe your son or daughter wouldn't want it either." Then people started to look at it differently. What right do we have to expose our children, to everybody knowing all our dirty laundry, as adults? It's one thing that we chose to do it, maybe unfortunately, when we were a young family and we were baring our hearts on our SSAH applications and that kind of thing. But to be respectful, there is no other way to do it. Are we talking full citizenship? You do not put people out like they are meat.

BEST PRACTICES:

Windsor-Essex Model for Adult Developmental Services.
Locally Designed • Community-Developed • Conducive to Government Policy
http://www.ont-autism.uoguelph.ca/WEFN-Brief-Aug2004.pdf

Going Home with Awareness

Discussion led by John Lord

Comments by conference members are arrowed and printed in italics

The goal of this next session is to really consider some action for change. We've talked about big ideas, we've talked about values, we've talked about principles about ways to build creative support, and ways to build inclusion. And we've heard lots of practical stories of success in a way, in the sessions this morning and this afternoon. I think part of the idea of this session is to inspire each other. Michelle talked just before the break about how important it is, in the Family Network group in Windsor, that families have a chance to talk to each other. The conversations or the talking with each other are ways to inspire one another. So I hope that you'll feel, that you can share from your heart today, or your questions, that can help us all move together, as to how we build those new stories. What we want to do is build some of those new stories. A lot of you handed in questions, and I'm not going to be able to deal with all of them, but I put them in some clusters. I'd like to start with those, and throw them out to you, and we can have some conversation about some of them. They're very good, some of these questions. And then we'll go to some of the questions in the booklet, we won't deal with all of those, but the booklet was really designed to give you something to take home, so that you can have some action steps for yourselves.

How does one ensure that the core values and vision that we talked about today are not lost, as they seem to be time and time again, in the kind of institutions that we create as humankind?

- *I think that we should share such innovation and leadership that permeates this entire community, and this movement, beyond our field. There's been a couple of outside fields, introduced here today, and I think we need to take that message beyond, to the seniors' field, to things like coaching, to mental health, to expand the vision.*

- *Make sure that the person's voice is always present, even as the values start to fade a little bit, if those voices are always there, that's going to be a corrective action. One way to do that, may be to make sure that a person has people around who know her/him really, really well and who care about them, and that will help also to keep the values and principles alive.*

It's true that both connections and creativity are central to who we are as human beings. And yet, creativity and connections are not necessarily central to corporations and bureaucracies. So one of the dilemmas we have is that a lot of the funding we get is from government. What we have to be able to do, I think, is make sure that that creativity and those connections are really, really embedded in every community. And it's possible. One of the ways you can tell it's possible is because some communities in Ontario really have very sophisticated networks, for example, of families connecting with families, or individuals connecting with individuals. And those communities have shown us, Durham region would be a good example, Windsor-Essex would be another. And I don't want to leave out any communities, but those just happen to be two communities that I know well, that have really nurtured through community development, the ability of family networks to work closely together. *Well Hamilton is like that too.*

Being creative should start when our children are born. How do we assist the Board of Education to include all people as part of the new story?

Wow! You know, in 1985, when we switched our child from the public board to the separate board, and eighteen other families did the same in Waterloo region, we thought we were starting a revolution. Because the Catholic Board welcomed us, and said inclusion is not only possible, but inclusion is the way of the future. And I tell you it saddens me deeply that twenty years later the inclusion is not embedded in every policy of every school board. And you have to fight in some regions, I'm told now, to be, to have your child included in local schools, and local high schools. So it's true, this is a very important question. I think education is one of those things, where we probably need provincial policy, because you're not going to convince every school board one at a time. Back in the eighties, we thought we'll just do one school board at a time, and eventually we'll have them all committed.

- *Gerard Kennedy is my MPP, and as part of our group in Toronto, I went to visit him, so if everybody in this room wrote him a letter, with their want and need, I bet he'd be open, because I found him to be very open when I talked to him, and he's assisting us right now.*

- *My son went into the regular Catholic school board years ago. Then, they were very accommodating, every class was brought down as he graduated, so it would be accessible, and he was totally integrated in every class. I went back recently, and now it's segregated. It was really sad to see how the school had gone backwards.*

- *To build on those thoughts, and tie it into today's work, I have a big worry. We could be doing a lot of work for how we would like our adult sons and daughters to be part of community, in a new way, with the new story. But it's a bit scary that younger families and children are learning the old story. We have to work on a broad canvas, because one ministry may be looking at trying to transform (and let's hope we'll see more new stories) but another branch of government is spending money on the old story. So in the big frame of things, there has to be some systemic work done in the other ministry.*

That's a very good point. We want to have everybody on the same page of the new story. It probably means some very strong advocacy has to happen. For those of us who are here today, mostly our commitment it to adults. But we obviously need to advocate with and stand with people who have younger children.

- *There actually is a policy on integration in Ontario, written by the Ministry of Education, that says integration is the norm in Ontario. That is supposed to be established for our students first. Only if all supports have been put in, and everything has failed, and if the parent wishes, do they look at segregated and other types of settings. But it's like a big secret, that people don't know, that the Ministry of Education's policy is integration as the norm. Maybe we should talk more about that, and challenge the teachers, principals and special educators, in these school meetings to put that policy back out front.*

- *My comment is about leadership. Lots of parents spent many years advocating in the education system, so that there are various advocacy bodies like the Special Education Advisory Committees and so forth. Perhaps they are a bit silenced by being within the system. Where we need to move forward, we need the leaders who have fought long and hard in that system, the parents that have volunteered and been advocating, to pass the baton. Leadership is sometimes about replacing yourself, and I think we need to replace ourselves properly, the people like the Marilyn Dolmages of this world, that have done so much hard work in the education system, when we finally need to move on and do other things, replace ourselves, train, get people up to speed, whenever parents come to the table, they're very often learning all over again, and saying, and taking the next five years to find out the same that we already know. So let's pass the baton better.*

Very interesting point. I thought that Judith Rosenberg's presentation about Spark of Brilliance was very interesting in terms of finding mentors, and in that case, it was mentors for inclusion, mentors in the arts community. But you're talking about a different kind of mentor: How do we mentor families to families, so that we can build that second-generation leadership?

I want to go to another question:

How do we find independent facilitators? We've been talking about how many persons and families really benefit from having someone who can listen deeply and help them plan and figure out how they want to live their dreams. How are you responding in various parts of Ontario?

- *We have a facilitator in our community. We advertised for such a person. We looked for certain skills--a person who had a very large network themselves, who really knew the community of Hamilton, knew what was going on, had grown up there, and was very outgoing, very friendly and stable. We wanted somebody who could handle being rebuffed and, most importantly, who had very solid values. The person that we did hire is a sibling herself, and it's been very successful with her. She's our asker-- that's so important---and she took so much stress away from the parents so they didn't have to always do the asking. As the Hamilton Family Network, we received a grant through the Foundations initiative, for individualized funding for ten families and a paid facilitator..*

- *On a smaller scale, in our area, ten families got together and formed a friendship network for their children. They pooled their resources, their Special Services At Home money, and hired a facilitator to coordinate the events for their children. So that took a load off the parents.*

- *There are also people around the province that you can hire. For example, Peter Dill, Judith McGill and others can be hired as independent facilitators.*

You might want to know that in British Columbia, starting 1 July 2005, there are going to be community living centres in each of seventeen different communities, and each one will have independent facilitators. But if you want to use your own facilitator, you can. You don't necessarily have to use the government-paid facilitator.

- *In Waterloo-Kitchener-Wellington, we have a new group, called P-L-N, which stands for Planned Lifetime Networks. We have four families right now who are lifetime members, and have created networks for their sons or daughters. Two of them have network facilitators, and now we are in the process of hiring two more. I am part of Foundations too, which is a Government-funded program, and I have a very good facilitator there too. I tell him my dream and or my son's dream, and he just goes out and gets it. And he's been doing this for two or three years. Actually I want to hire him, and keep him for life, never mind the rest!*

- *I am Christy Barber from Toronto, and I facilitate the Safe and Secure Futures Networks, which are funded by a City of Toronto Community Services grant. So ten hours a week of my work is involved personally with families, assisting them to develop a support network. I also to facilitate two networks, held monthly in two different parts of the city, and we are an autonomous family network, as John described. One of the interesting outcomes is, as we come together, and in a trusting, comfortable environment, and in fact, I'm thrilled because three or four members of our networks are here today. People come forward and support each other. Someone who's reluctant, as we all are, when we think about starting a network, people are saying I'll come, I'll go, we'll*

do it, I'll come and help you. So people are coming forward and realizing that, if they've had a good experience themselves and feel supported, they are then in a position to reach out to someone else.

- *We are part of Families for a Secure Future, which is across three regions right now, Durham being one, Guelph-Wellington-Dufferin being the other. We're a group of family-driven groups, each in our own home communities, that come together to support our individuals through whatever planning is needed. Judith McGill is one of our facilitators. And her role is to support our individuals in their life path, and to help us as parents to take that next step in the planning for their future, so there are groups out there, and they're not hard to organize and become part of a group. So I say to all the parents, just keep out there and keep working and networking--it's your best form of support.*

- *I just wanted to reference the Individualized Funding Coalition for Ontario, which is doing some outreach to the families who were part of the Workfest in February 2004. I would suggest you might leave your name with the Coalition, and we would find a way to include you in some gatherings of families that we're in the process of setting up across the province. I'm not saying that it gives you direct access to facilitation, but it's a context for families where families are going to be encouraged to come together, and within that, I'm sure that facilitation can be developed. I just want to express a caution. Sometimes we can end up kind of mystifying the notion of facilitation, and thinking that, if only I had one, everything would be fine, and it ain't so. But many of us are called, actually, as family members, to facilitate our own bringing together and development of plans. I think we just have to trust ourselves a bit more.*

That's a very good point. This is probably not one of those things that we want to professionalize, and certify. As we do so much in this society, if something is good, we like to certify it, and then we like to accredit it. I think Peter's caution is a good one: we really want facilitation to be grounded in people's lives and in community, and in connections, and that's really going to happen because people know people. So my daughter, for example, is a fantastic facilitator with my circle, I don't want somebody coming along and saying, she can't do that, right? Because she's good at it, and she can do it. And so can lots of you in this room, play that role. There's also a small, little movement going, on, that started in Windsor, but it's now in other communities, where we're actually doing some training for volunteer facilitators. A couple of days of a workshop, that kind of thing, where people can learn some skills of deep listening and facilitation. So if you're interested in that, too, you can probably track it down, through the Individualized Funding Coalition website.

Let's go to this little guide you can take home, to help you remember the things you learned today and keep them going in your life. Let's go through three or four of the questions, to warm us up for going home, because going home sometimes isn't easy. You've had a stimulating day, and you've met lots of new people, you've heard lots of new stories, and now you want to go home and be able to act on those stories. That requires some intentionality, to try to be intentional about how we go home, and these are some questions to help you begin that.

All change begins with ourselves. What did you learn today about yourself that you would like to carry home?

I'd like you to ponder that and then I'll ask three or four people to share what they'd like to carry home. The purpose is just to stimulate and inspire us to think about our own hearts--it's not going to be the same as somebody else's, but it might just give you ideas.

- *I learned that I don't always give my son the credit that he deserves, with respect to his decision making processes, and*

that I realize that even though I thought that was a good idea, that it really is a good idea, and that I'm going to be more mindful and open and hopefully diligent about that. So thanks a lot.

- *I want to build a stronger relationship with my daughter.*

- *I learned many things today, but one of the things that I did learn, and I probably want to share this with a lot of the parents here today, is I've been affirmed a little bit today, that, affirmed to the fact that I am on the right track, and I am doing the best I can at this moment, and I'm going to go home, with that knowledge that I have to keep advocating, I have to keep going in a straight line, and we will have hills and valleys along the way, but I'm not going home depressed or thinking that I've got the rest of my son's life, and my life to plan, but I'm going home today, feeling that I'm not that far off, and I'm not doing that bad a job.*

- *It's hard sometimes hard to explain] my ideas to others, who think I'm off on the wrong track, and as the previous speaker said, it's nice to know that there's a whole bunch of other people who think that I'm not on the wrong track.*

I learned language. You know, in the world of social change, this is very important. If you look at the history of any social change movement, the women's movement, the civil rights movement, any social change movement, it started with language. Women in the 1920s said, we want to vote, women in the 1960s said we want to be equal, on and on, right, the language that we use, the language that we use is very, very important. It's really the beginning of the new story. And you know, don't beat yourself up, because not everybody's going to understand it right away. We had a support circle for eight years with our daughter, and my brother-in-law, whom I love dearly, came to every single meeting for eight years, and about two years ago, after eight years of coming to all these circle meetings, with all the new story language that we thought was there, he said, "Well when is Karen moving into a group home?" That was a very startling thing for me, and I'm sure for you, as you try to sell your ideas to your friends, that the old story is very embedded in the culture. My brother-in-law isn't a bad person, he's a fabulous person, he's a very progressive person, but the old story was very embedded, and I had to shake him to wake him up, and I think he's starting to get it. But, it takes time, it takes time. And the problem is, that the old story is also embedded in our lives, right? So there will be times when we will slide, and again, don't beat yourself up on that, but just to remind yourself, uh oh, there it is again, there it is again, there's the old story, it's like a film, there it is again. Just notice it, just notice it.

- *Actually, it was exactly the same issue and it was after listening to a very profound presentation from Judith and thank you very much, because I think we're asked to do deep listening, I'm not sure sometimes we listen to our voice enough, and be aware that, if anybody has read The Four Agreements, be impeccable with your speech so we have to listen to ourselves and our voice, and catch ourselves, because the old tapes are there, and so I want to thank Judith again, for just an amazing job this morning. Thank you.*

- *Yes, I want to say the same thing about Judy, Judith Snow. I felt that you gave short, sentences, but they mean so much, and you talk straight up, you say it, that's the way it is. The way that you presented it, you challenge us a lot. I come away feeling that I have changed my thinking. I think that is one of the important things I have to do.*

"Being aware" is critical to moving toward the new paradigm and the principles outlined above. In what way does your situation reflect the traditional paradigm, the old story?

The second question about being aware is critical to moving towards the new paradigm, and the principles outlined above. In what way does your situation reflect the traditional paradigm, the old story? I'm not going to ask any of you to share on that, because I know there are a lot of old stories in the room. The reason the question is there, is for you to ponder, and to be able to notice when the old story emerges. And you might have noticed, for example, in the last session, where we heard some stories from around the province, some very interesting stories, that some of the stories were the new story, and some of the stories had a twinge of the old story. So just notice it, and as we get better at understanding the new story with self-determination and community and citizenship, we'll begin to notice the old stories more effectively. We'll become more attuned to them, and again, we don't have to be hypercritical, but we can just notice, and we can even have some compassion for them.

I heard a lovely story recently about some people who have sons and daughters in institutions, for example in Ontario. And these moms and dads are very upset that the institutions are closing. And they said that in a meeting. And speaker after speaker disagreed with them. But there were two other women in the room, who said, we need to spend time with you, and we want to listen to your story, we want to listen to your fears, we want to listen to what's troubling you. So because somebody comes with an old story, we don't judge it, we hear it, we listen to it, we try to understand it, we listen to it. And that's a journey that's continuing, but the two women who listened to that story, are now connecting with those women, and those women, and those men and women, whose sons and daughters are in institutions, are beginning to piece together what something might look like for them as their sons and daughters come home, and that will be a long journey, because that's a very difficult story to change, if your son or daughter has lived in an institution for twenty, thirty, and in some cases, in terms of Southwest Regional Centre, forty-five or fifty years.

Discerning or deciding what kinds of supports are required is an important part of the process of learning.
What skills and strengths do you have, and which type of support do they best fit?
<u>My strengths and skills</u>
<u>Types of Support</u>
Planning support
Community connecting support
Direct practical support
Peer support

Again, this is the kind of question that is really a Zen question, if you know anything about Zen. It's a Zen question because we're not going to answer it, but you're going to answer it for yourself. And a Zen question is like something you drop in the water, or you drop in your heart and you don't try to answer it in your head. You just ponder it, and someday when you're walking by the river, or someday when you're driving on the highway and the sun is beautiful, the answer will come to you. Because the answer to the questions won't just come by thinking, the answer will come by thinking, by it emerging in terms of who you are.

There's a young woman that I know, who's having a real struggle right now, because her job description has her playing two roles, on the right-hand side of that question. It has her being a planner, and a direct practical support worker. And she was totally confounded and came to me, and said, I'm really having trouble with my role, and it took me only five minutes to realize what was going on. And she had met with her boss on six occasions, to try and figure it out, and he couldn't figure out what the problem was. The problem was, that she's planning with this person, and then she's being the support worker for the person at the same time. And the roles are getting

mixed and unclear, and so she can't be creative on one end and the other. And so once you know that, you can bring some wisdom, you can bring some wisdom to it, you can bring some wisdom to how you're planning, or you can bring some wisdom in terms of maybe even restructuring that role, in terms of what you're going to do in the future.

We all desire to make things better for ourselves and others.
Given the principles, and your strengths, what is one thing you would like to change to build more creative supports for someone you care for in your community?

We heard some people talk about how they wanted to change their relationships, or their vision. Is there anything people have thought about when you ponder that question? What would you like to change to build more creative supports for someone you care for?

- *We support folks of all ages with autism, and there's a huge problem I see coming. This conference is about supporting adults, but I see a bifurcation in the autism movement between the younger families and the older families. A lot of good work has been done, in things like IBI for the younger families. But for those families who saw it as being a cure, they're soon going to find it's not a cure. I think we can do a lot to help them understand that, for most of them, it's not a cure, and they're going to be wrestling with the same problems in the not too distant future that we have been wrestling with. There's a whole range of supports and services which need to be put in place, which they really haven't. They've been so focused on IBI and changing the child to suit the environment. There's a lot more work ahead to help them understand that they need to think about changing the environment to fit their child, and all those sorts of supports and services that are needed. Some of those families have focused so much on what happens in the younger years. We need to reach out, to help them bridge the probable crisis that they are going face over the next couple of years. Yet probably what many of thee younger parents see is that we're the old-timers, part of the old paradigm which really doesn't work. But with more progressive parts, of what we're doing, I think we can probably reach out and help them bridge the gap. I think that we probably need to reach out to them more than they're likely to reach out to us.*

- *I'm just remembering the first conference that I ever went to, when my son was just a baby, and he's twenty now, and how confounded a mentor of mine was. It was a room like this, discussing parent support, and the issues of all the young parents were being bantered about. Then a woman stood up at the back of the room, in her seventies, and cried, and said "We're talking about the same thing, why aren't we talking together?"*

Building relationships and allies is an important part of creating change.
Can you identify one professional who believes in the self-determination of individuals and families with whom you could talk about the paradigm shifts that are occurring and your idea for change?
Can you identify two individuals or two families who you could talk with to affirm each other with mutual values and awareness?

As you go home, I want you to think about who you can invite to be part of your changed process. Finding allies--finding people in your community who can be allies. Sometimes it's better if that person is not in the disability field, the minister of your church, your next door neighbour who works for Bell Canada, you know, the Rogers Cable executive around the corner, the executive director of the social planning council. Think of all the places, the civil society groups in your community that might be interested in these issues. And you'd be surprised how much of a dialogue and a conversation you can have, because these are very interesting issues. Especially if you just pop it on the table as you're having a conversation. By the way, you know this is an aging society, we're all getting older, and by the year 2020, almost twenty percent of Canadians will be over sixty-five. So you just slip that in there too, because forty-five percent of people over seventy have a disability of one kind or another. So the issues we're talking about, are not just issues for our sons and daughters, they're issues for an aging society. There's going to be lots of people, who are going to be interested in having conversations and becoming potential allies.

Can you identify two individuals or two families, you could talk with to affirm some of the things you've learned today? That would be another strategy.

- *It came to mind, I just met someone yesterday, that has a new position with the City of Windsor, and it could be that other positions are going to come up like that in municipalities. The job title is the Diversity and Accessibility Officer. It's an awesome place to start talking about citizenship and including people with various disabilities in the diversity as well as the accessibility piece. And so I just think it's kind of neat because it's really coming out of the Ontarians with Disabilities Act, but it has much broader things for all of us to enter into.*

Now that's a wonderful example of how we need to reach out. You know, diversity training is one of the fastest growing training things in the corporate world, because the corporate world is learning that, wow, if we serve women, and if we serve minority groups, and if we serve people with disabilities, we're going to have more business. The corporate world is now doing a lot of diversity training. If they're now in cities and communities, that's a really positive direction.

We build change by working at different levels of society. All are important, and they give coherence and strength to citizenship and inclusion when they are all working together. How can your community move ahead on all these levels?

Individual and family change
(families meeting together, individuals having genuine choice, individuals and families creating support networks, having facilitation support, etc.)

Organizational change
(organizations believing in the vision and values, leaders being open to dialogue about change, resources being shifted to individuals and families, etc.)

Community Change
(community settings are accessible to all, schools embrace inclusion for all, recreation, leisure, and workplaces welcome diversity, mechanisms exist that assist people to experience full inclusion and participation, etc.)

Policy change
(portability of funds is a provincial policy, as well as independent planning and individualized funding, etc.)

We have to work at all these levels. Working to advocate for policy change at the provincial level is important too—such as through the Individualized Funding Coalition for Ontario, the Family Alliance for Ontario, and Community Living Ontario, as well as some of the organizations for specific special-needs groups.

- *Another pitch for the Family Alliance newsletter. There are lots of stories in our newsletter, and the newsletter can be used as a way to educate your neighbours, your local Member of Provincial Parliament. We really encourage people to use it creatively as an educational tool.*

So this is a guide for you to take with you, as kind of a way to think about the different levels of change, and for you to think about where you want to bring your energy. Because one of the things that creates change--and the theme of today was to build creative supports--one of the things we know that does that is having lots of people to participate. Some of you will participate on the level of your own family, and you'll work away at thinking about how to build a support network. Some of you will work more at the community level to try to build autonomous family groups, or autonomous people first groups. Some of you will work at the policy level, by being involved in some of those organizations and obviously all of that work is needed at all different levels.

- *People First of St Marys has developed a book on **How I Want To Be Treated**. It is a great book and could be used in all kinds of ways.*

I've seen this resource, and what I love is its how-to of self-determination. The self-determination is the value, the principle is listening deeply, and supporting people to have power and choice. The how-to is a booklet that educates people with disabilities. I'm going to change that, because Judith said we don't need to use the word disability. That supports persons or individuals in practical ways to know what their rights are and how they should be treated.

That's a wonderful way to end our day, because it really brings together all the different levels of our work, the values, the principles, and the how-to. I wish you well in your pathway as you go home today, and as you continue this journey.

Displays and Poster Presentations

We invited groups and organizations to display information and success stories about their creative initiatives, such as:

- "deep listening" to vulnerable persons who do not speak
- helping self-advocates to direct their own supports
- creating and maintaining circles of friends to support good lives now and in the longer future
- circles of support for vulnerable persons who have no family
- creative options to have a home of one's own
- independence technologies
- recruiting volunteers to be informal friends
- ways to screen, train and appreciate excellent volunteers
- bridging gaps between adults with special needs and their neighbourhoods and communities
- supporting adults who want to continue learning, formally and informally
- enabling people to develop micro-enterprises
- artistic self-expression as therapy
- contributing to our communities
- lifesharing communities in households or larger units
- planning for good transitions—from school to adulthood, and for life after parents age and die
- caring for the caregivers
- how brokerage works
- what aroha/microboards can do

Displays were grouped to match the four workshop themes.
* indicates more detail is printed below in alphabetical order
† see workshop

Planning with the Person and Support Circles
Inclusion Network—with MAPS, PATH, CIRCLES
*Consumer/Survivor Initiatives in Mental Health
*Planned Lifetime Networks (Waterloo-Wellington-Oxford)
*Safe & Secure Futures (Extend-A-Family, Toronto)
Speaking Differently
Support Clusters Network—Canadian Mental Health Association
*Ubuntu Initiative

Homes Not Just Housing
*Aspergers Society: Housing Committee
*Dave's Success Story
Guelph Services for the Autistic (as housing trust)
*Homes for Life, Peterborough
†Housing Options, Community Living St Marys and Area
*Independence Technologies by Hamilton Health Sciences

Meaningful Work and Recreation
Micro-enterprises
*Community Music Therapy Services (CMTS)
Energy therapies, e.g. Reiki and Therapeutic Touch
*Exercise Therapy: Mind, Body and Spirit in Balance
Job-Fit, an initiative of the Learning Disabilities Association
*Ju-Lis Delights, Guelph
*Options Mississauga
*Rebecca's Dream: new video ***Revel in the Light***
*Spark of Brilliance, Guelph

Co-ordinating Sustainable Good Lives
*Transition initiatives and resources
*Aroha entities of personal empowerment and support
*Autism Society Ontario
*Balancing Act: Personal Coaching & Workshops for Caregivers
*Families for a Secure Future
*Family Networks of Family Alliance Ontario
*Individualized Funding Coalition of Ontario
*Special Needs Planning Group
St Francis Advocates: Stepping Stones
†Windsor-Essex Brokerage for Personal Supports
†Windsor-Essex Family Network

There were also book displays from Parentbooks and AACI

Aroha Entities of Personal Empowerment and Support

- A mechanism that can keep a good life going beyond the parents, by giving committed friends sufficient legal powers to act with and for the vulnerable person
- Functions like a microboard (BC) or self-directed support corporation (some US states),
- Aroha is Maori word (Aotearoa/New Zealand) for love, caring, friendship, commitment and community in active not just abstract ways
- Can be incorporated under Ontario laws (though cannot be a charity for tax-creditable purposes as for benefit of one person)
- Can own a home, receive and manage support funds, hire and employ support workers, advise on best use of trust funds.

http://www.ont-autism.uoguelph.ca/entities.shtml

Aspergers Society of Ontario: Housing Committee

A group of parents of adults with Asperger Syndrome (AS) and individuals with AS who are concerned about the lack of housing. A committee of the Aspergers Society of Ontario, chaired by Dr. Kevin Stoddart.

The focus of our work is to create supportive housing, tailored to individual requirements for personal space, attention to sensory sensitivities, and unique personality traits. We feel that most adults with AS want to live in a self-contained unit (i.e., kitchen, washroom, bedroom). For those who choose to share living quarters, the building they share should have both private living spaces for each person and common areas to provide opportunities to build social skills, relationships with others, and other life skills. An essential part of our model is to build a circle of support for our sons and daughters.

We have been researching various supported living options that would meet the specific needs of adults with AS. We have visited Rougemount Co-op and Deohaeko Support Network; are establishing relationships with key community organizations; and have contacted and met with politicians. *Display by Sim Wong of Toronto*

ASPIRE: Autism Support Project: Information, Resources, Empowerment

A pilot initiative begun in August 2002 in Waterloo-Wellington, by Guelph Services for the Autistic with funding from Waterloo Wellington Autism Services.

Its broad goals are to support adults and older teens with ASD, with their family members and friends, to:

- Express their priorities and goals for good lives
- Make informed choices among available funded services
- Create relevant supports that may not be available from the traditional service system:

ASPIRE has made possible PATH events (Planning Alternative Tomorrows with Hope) for persons and their families and friends. PATHs are facilitated by professionals using the strategies that were pioneered by Inclusion Press.

ASPIRE's distinctive hallmarks are:

1. Concern for a whole life that suits each person's unique abilities, interests and needs, as these are known from the person herself/himself;
2. Respect for the personal support network of family and friends as a vital resource and safeguard for quality of life now and in the future;
3. Creative, individualized ways of ensuring that adults with autism have the most appropriate and empowering choices on all elements of a good life, including:
   - a personal support network of friends and family
   - a home of one's own that reflects one's preferences and needs
   - ways to express thoughts and feelings, make informed choices, and be heard
   - ways to continue learning and growing
   - ways to contribute meaningfully to the community
   - a safe and secure future.

http://www.ont-autism.uoguelph.ca/aspire-project.shtml

Autism Society Ontario's Adult Project

In May 2004, ASO began a project to promote, develop and enhance services for adults with ASD in Ontario. Activities include:

- Compiling a list of adult service providers in Ontario, key volunteers and/or advocacy groups on adult issues related to Autism Spectrum Disorders.
- Planning a survey to learn about numbers and needs in various Ontario regions. Discussions so far have shown the top issues to be Individualized Funding, specialized supports for adults, more networking/communication, better affordable housing, more support groups, information on ASD numbers and best practices, and increased advocacy re: ODSP regulations and income/employment supports.
- ASO's manual focusing on living with ASD in the adult years, including personal accounts and success stories, should be available by May 2005.
- ASO has advocated to the Ontario Government on adult issues--to MCSS on *Transforming Services in Ontario for People who have a Developmental Disability* in November 2004, and in most of the policy forums in this process; to the Legislative Committee on the changes to the *Ontarians with Disabilities Act* related to the MCSS's planning for Ontarians with Developmental Disabilities; and to Ontario's Minister of Finance.
- In partnership with The Autism Group, ASO produced first hand accounts of adults on the Autism Spectrum in a booklet and a video.

http://www.autismsociety.on.ca/

Display by Patricia Gallin of London for ASO.

Balancing Act: Personal Coaching for Parents/Caregivers

Balancing Act is a firm that offers personal coaching, consulting and training to individuals, groups and organizations, will introduce this growing new field of coaching and personal development.

Shirley Edwards offers coaching methods and tools to help parents and caregivers find that elusive balance. As in our advocacy efforts, the individualized approach rules.

Shirley is a trained Personal Life Coach and certified non-profit manager with an extensive background in program, project and organizational development and management in the non-profit disability field.

Shirley is a member of the Individualized Funding Coalition of Ontario. Her passion is supporting others to create the lives that they want. As a parent of an adult son with multiple disabilities and a caregiver/coordinator for an aging parent, Shirley knows first hand the "roller coaster' of balance and change in living with disability and health challenges.

Since 2000, Shirley has been studying and working in the Personal Development field with a passion for bringing the benefits of this work to fellow parents and people who face challenges and change in their lives.

Consumer/Survivor Initiatives in Mental Health

From Madhouse to Our House is a new DVD launched March 2005, to illustrate evolution in mental health care. A rare look at consumer/survivor initiatives in mental health, it was produced as a new way of introducing an emerging model for mental health care to a wide audience.

Consumer/survivor initiatives (CSIs) transform in a fundamental way how people with mental health concerns are supported. They go from being consumers of services and survivors of the system to active participants who support one another and work for community change.

"While there are many efforts underway to reform or improve mental health services, this one is unique in that it puts consumers in control of their own supports," said Geoff Nelson, a psychology professor at Laurier and the principal investigator of a five-year study of CSIs. "With the help of the government, individuals who have experienced mental health issues have developed their own organizations, ones that are operated exclusively by and for mental health consumer/survivors."

While such initiatives have surfaced around the world, they are relatively new and limited in number. Ontario became the first province in Canada to fund CSIs in 1991 and is now home to 60 initiatives.

Information provided by Dr Joanna Ochocka, Project Manager, and Director, Centre for Research and Education in Human Services
73 King St. W., Suite 300, Kitchener, ON N2G 1A7
http://www.crehs.on.ca/

Community Music Therapy Services (CMTS)

A non-profit charitable organization, comprising a small group of music therapists and a board of directors, and encompassing the Waterloo and Wellington regions. The mission of CMTS is to provide music therapy services to persons with special needs and to promote music therapy as a profession. Beginning in the Fall of 2005, CMTS will be providing services to persons of all ages.

Specifically for adults, music therapy can enhance the quality of life, increase self esteem, provide an outlet for emotional and self expression, and support physical and cognitive functioning. Creative experiences in instrumental playing, improvisation, singing, movement, and song-writing are used to support all goal areas.
Contact: Susan Lemessurier-Quinn, 822-8873

Dave's Success Story

Dave's family had a vision in 1974 and he has achieved their dream. Dave continues to prove his life is flourishing and successful. He has his own home and micro-enterprise/small business. He runs "Dave's Deliveries" with support from one of his personal assistants. Dave (now 30) rents his small comfortable accessible home, and lives on his own with support from personal assistants, friends, relatives and neighbours.

Dave's courage and determination to live in the community led to his achievement of independence in his own home 2001. To many (like the doctor who diagnosed him) this would seem impossible. To him and our family a much desired and achievable objective. We keep on repeating loud and clear "just keep watching, Dave will achieve more!" Dave is a shining example for others to follow.

Dave's story is published as ***A PLACE CALLED HOME: for families of children with a disability and the professionals who serve them,*** by Alison C. Ouellette, 2002. *Send cheque for $12 CAN plus $3 shipping/handling to A.C. Ouellette, 10810 Riverside Drive E, Windsor, ON, CANADA N8P 1A4.*

Exercise Therapy: Mind, Body and Spirit in Balance

Fitness professionals spend a great deal of time motivating, inspiring and assisting others in their pursuit of improved health. We educate individuals on the benefits of regular activity with hope to increase their current and future level of health.

Wellness is the search for enhanced quality of life, personal growth and potential through the behaviours and attitude of positive lifestyles. To achieve balance in our lives, we need to take care of our Mind, Body and Spirit. Our bodies gather physical strength through physical activity and exercise. If we continue to challenge ourselves physically, our bodies constantly change and evolve positively. These responses to physical activity keep us healthier and more easily able to meet the demands of each day.

Whether one has physical disabilities, mental health or cognitive and sensory impairments, exercise has a place in our everyday lives. Exercise stimulates the cardiorespiratory system and muscular and skeletal strength. It also improves balance, coordination, agility and flexibility for easier mobility and reducing depression and anxiety while assisting in stress management.

Minerva Gardiner of Guelph presented a display.
(519) 822-9975

Families for a Secure Future

Families for a Secure Future is committed to reaching out to and supporting individuals with developmental disabilities and their families by establishing a network of local family groups across Ontario. These mutual support groups come together to learn and to support one another to take the next step toward imagining and creating a better future for their sons/daughters. Families for a Secure Future is based on the fundamental principle that individuals and their families can define and prioritize their own needs. It is believed that individuals can make choices and direct their lives with support. To this end, Families for a Secure Future is governed by families and individuals themselves.

Dedicated to serving vulnerable adults with developmental disabilities and assisting them to take up their full citizenship in the community. It is a family-governed, provincial, non-profit charitable organization that is based on building networks of support for both families and individuals so that there are people that care about them and will help them to make secure plans for the future. Our vision focuses on supporting individuals within the context of their family/friends to develop an individual plan for moving forward and creating a meaningful life for themselves. This plan evolves over time and looks at both the immediate and the long-term future. Through support to local family groups, families benefit directly by increasing their opportunities for learning and their network of support.

Visit the website at http://www.familiesforasecurefuture.com/

Active in the Wellington, Dufferin and Durham regions of Ontario.
Display by Nancy and Marvin McDougall.

Family Alliance Ontario

www.family-alliance.com

Who we are:

Family Alliance Ontario is a support group of individuals, families and family networks dedicated to fostering the strength, stability, competence and knowledge that we can offer each other. Our membership comprises and welcomes all people who share our values and goals.

Our Mission:

We are an alliance of citizens that offer knowledge, tools and networking opportunities to individuals with disabilities and their families to assist them to realize a vision that includes having valued relationships, choice and control in their lives and enables inclusion through meaningful contribution and participation in their communities. There are 15 local family networks in Ontario directly affiliated with us and many more family groups who share our goals.

Current Goals:

- Create a strong family voice
- Support individuals and families in building their capacity
- Support the work of local family groups and networks
- Work for individualized supports to achieve inclusion

Copies of the Spring 2005 issue of The Compass were available for all participants. Display by Barbara Ostroff

Homes for Life

We are a group of 23 families in Peterborough with teenagers and young adults who live with intellectual/physical disabilities. We came together to plan and advocate for appropriate, safe, affordable, accessible and inclusive living options for our sons and daughters.

We provide collective support for those facing transitional changes, brainstorming community resources and facilitating long-and short-term planning, both for the group and for individuals. As families begin to know one another, we hope for partnerships to develop, leading to resource sharing and creative living opportunities.

We want homes in communities where a spirit of mutual support and a respect for individuality and differences in others will lead to rewarding, interdependent relationships. We demand more individualized and flexible funding, consistent with a citizenship perspective. Person-centered, individualized support and personal support workers/facilitators for people who require assistance throughout their lives are priority issues. Our goal is to create meaningful lives for our daughters and sons, no matter where they live.

Information by Marilyn Atkins.

Read more at

http://www.communitylivingontario.ca/Daily_News/2005/July/July4a.htm

Independence Technologies

A program of Hamilton Heath Sciences that specializes in Electronic Aids to Daily Living (EADL), also known as environmental controls. EADL enable people with physical and/or cognitive limitations to control a wide range of electronic devices in the home, school or workplace. Devices may include alarm calls, telephones, door openers, stereos, TVs, VCRs, electronic beds, lights, tracking systems and appliances. EADL range from simple, off-the-shelf solutions to more complex systems. The program offers a complete service:

- Professional assessment by an occupational therapist and a rehabilitation technologist.
- Sales of an extensive range of products ranging from simple to complex
- Service and installation
- Education

Independence Technologies:
Elizabeth Steggles, Manager
Hamilton Health Sciences
Osler Building, Suite 114/111
Box 2000, Hamilton, Ontario, L8N 3Z5
Telephone: (905) 521-2353
E-mail:steggles@hhsc.ca

Individualized Funding Coalition for Ontario

A group of dedicated volunteers--persons, families, friends, organizations and agencies--all working together to make Individualized Funding a reality in Ontario. All members sign the following accord:

"The Individualized Funding Coalition for Ontario supports the self-determination of persons with disabilities. We believe that all people should have control over decisions concerning where they live, with whom they live, with whom they associate, and how they spend their lives. In order to achieve this we recognize that Ontario must develop a system of funding whereby the person requiring assistance, supported as appropriate by family and/or significant others, has access to and control over the funds allocated for his/her supports."

IFCO holds conferences and training workshops building capacity for individualized planning, funding and supports and the development of support networks or circles. IFCO has developed many valuable resources at: www.individualizedfunding.ca
Display by Joyce Balaz who maintains the IFCO website.

Ju-Lis Delights

A charitable organization which creates employment opportunities for physically or mentally challenged persons by recognizing their abilities. We produce Exquisite hand made Belgian chocolates, that are offered in the Guelph Market on Saturday mornings and alos made to order. We hope to have a core group of employees, who will then be able to train new persons with disabilities. Ju-Lis Delights will employ as many individuals as the market demand will justify. The trained individuals will have learned skills to make them more readily employable in the community.
Contact: Elisabeth Niimi of Guelph, 519-821-4822.

Options in Mississauga

Options was founded in 1991 by a group of parents of developmentally handicapped, including autistic/PDD, adults who were concerned about the lack of opportunities for their children after age 21.

Options is a Registered Charitable Non-Profit organization. In 1994, a store was opened in Port Credit, Ontario, providing business services such as faxing and photocopying while giving valuable job experience and skills to D.C. adults. Trainees work on cash registers, computers, do faxing and photocopying, working at their own level. They also provide flyer delivery and yard work services.
Options also provides opportunities for Life Skills Training and Recreational Activities.
Thelma Wheatley, past-president, explained and illustrated Options in the session after lunch.
http://peel.cioc.ca/details.asp?RSN=17248&Number=135

Planned Lifetime Networks (Waterloo-Wellington-Oxford)

An incorporated not-for-profit charity in Ontario and affiliate of PLAN[tm] of BC, which has pioneered the formation of personal support networks for people with disabilities since 1988. Visit PLAN's website at www.PLAN.ca

Members of Planned Lifetime Networks envision a future in which people with disabilities:
-Enjoy financial security
-Live in a home that is a sanctuary
-Participate in a caring and hospitable community
-Are supported by family and friends
-Have their wishes and choices respected
-Are protected from abuse and exploitation
-Make contributions to their communities
-Have families who enjoy peace of mind.

Planned Lifetime Networks will support families to develop quality of life and safe and secure futures for their relatives with disabilities. We will:
-Assist families to plan for the future
-Connect families to others in similar circumstances
-Support people with disabilities to understand their options and make choices
-Facilitate the establishment of a loving and caring personal support network for each person with a disability
-Provide advice and referral on developing wills and estate plans, creating discretionary trusts, and maintaining government benefits
-Provide advice and referral on alternatives to the current government-administered social services
-Monitor the quality of programs and services a person with a disability receives, particularly after their parents and family members are no longer able to do so.
-Provide recommendations and advice on home ownership and legal guardianship options
-Monitor trends in tax and trust legislation, and work for better tax breaks for families who care for disabled relatives
-Create a greater community awareness of the contributions that can be made by people with disabilities.
5-240 Erb Street West, Suite 306, Waterloo, Ontario, N2L 6K6, phone (519) 746-1188, email plnwwo@sympatico.ca

Rebecca's Dream

Rebecca is a 23 year old woman who has overcome typical cultural attitudes and has created, along with her family and support circle, an exciting life, working at meaningful jobs in the community, developing wonderful friendships, planning for her move into her own apartment with friends in 6 months and much more. Rebecca's story is very inspirational and is one that all can learn a lot from. The story of Rebecca's contribution to her community as artist, dancer, dreamer, teacher and friend is told in her new 13 minute video called "Revel in the Light." Her experience with circle building, tools for planning and the ins and outs of individualized support and community building is very helpful to others. Rebecca's new video will be shown in the session after lunch.
Rebecca and her support group are members of the Ubuntu Initiative.

Safe and Secure Futures Networks aim to empower families to develop and nurture a support circle with their family member who has a disability. Circles support the person to have choice and control, and to experience a variety of meaningful relationships. The Safe and Secure Futures Networks offer monthly opportunities to share and learn from each other, building our confidence to invite people to listen to hopes and dreams, consider possibilities, and plan with the individual we love. Meeting focus topics offer something to "suit" everyone:

♥ Relationships-The heart of the matter
♦ Ensuring Financial Security and Estate Planning
♠ Creating the right place to live- and the right support
♣ Person-centred Planning-with a support circle

A Good Life by Al Etmanski, informs and guides these forums for mutual support and information sharing.
Individual support circle facilitation may be arranged.
Extend-A-Family receives funding for Safe and Secure Futures through a City of Toronto Community Services Grant. Christy Barber, Coordinator

Spark of Brilliance

A Guelph-based initiative launched in 1999 to promote mental health through creativity, conceived out of a belief that involvement in creative expression can play a pivotal role in the healing process. The program is intended to empower persons dealing with serious mental health issues, and the family allies who support them, in discovering an interest, a talent, or an untapped resource, and to foster creativity. They believe that within each person resides an untapped potential and creative spirit. The Spark of Brilliance initiative seeks to uncover and spark that creative spirit, and help make it manifest. Components include:

* Educational Workshops
* Creative Workshops
* Creative Mentorship
* Community Partners
* Outreach Sharing

Judith Rosenberg, founder and co-ordinator, set up a display and presented a video about Spark of Brilliance in the session after lunch.

"Special Needs" Planning Group

An organization that is made up of parents of people with disabilities. Our focus is to assist families in preparing financial and estate plans that will ensure that their sons or daughters with a disability will enjoy a decent quality of life now and in the future. Our plans make use of Henson Trusts, Wills, Funding Mechanisms like family estates and life insurance programs and Life Plans which are designed to provide for our children after we are gone without affecting entitlement to ODSP benefits.
We do not charge any fees for our services, which means that everyone can take advantage of our knowledge and expertise no matter what their financial situation.

For further information, please visit our web based resource materials at www.specialneedsplanning.ca or email Graeme Treeby at graemetreeby@sympatico.ca

Transition Initiatives and Resources

A transition is any event that results in changes to relationships, routines, assumptions or roles. Transitions are a normal part of life and occur throughout the life cycle. While any individual can have problems with transitions, those with special needs often have more difficulty managing transitions in their lives.

Current research shows that effective transitions are planned, collaborative efforts and are comprehensive in scope.

T_Taking advice from the student, teachers, family, therapists and community.

R_Re-assessing student academic, social, vocational, and interpersonal skills.

A_Adapting to new students, authority figures and environments.

N_Noting and evaluating the process.

S_ Starting long-range plans early to give students knowledge of available supports.

I_ Individualized Program Plans that meet individual needs.

T_Taking responsibility for lifelong learning.

I_ Involves students in planning for their future.

O_Open discussions with teachers or community members at the receiving end.

N_Non-confrontational and effective models of advocacy.

Nancy Cherry, currently ASPIRE Advocate for GSA, researched and designed the Transitions display to apply mainly to vulnerable teens and young adults. She acknowledges the following sources for the first two paragraphs: Schlossberg's Transition Theory, 1995, which is also discussed in Transition Planning for Students with LD
http://www.education.gov.ab.ca/k_12/specialneeds/unlocking/unlock_7.pdf
Mental Health Foundation of New Zealand
http://www.mentalhealth.org.nz/page.php?p=93&fp=94&sp

Aspects of effective TRANSITIONs are taken from *Effective Practices in Special Education Programs* No. 1 Fall 2001
http://www.education.gov.ab.ca/k_12/specialneeds/practices/transition.pdf

The Ubuntu Initiative

We started as a small group whose lives are intimately bound with highly vulnerable people. Some of us, for up to twenty years, have been accompanied by Peter Dill and engaged deeply with one another in our efforts to discern and build on all that is good in the lives of our sons and daughters. Together, our little group holds many lives. We "share the same truth", i.e. the experience of collaborating with particular individuals who have a developmental disability in ways that bring life to us all. We are friends. We are deeply committed to people who are vulnerable, to family life, to friendship and community. Although many of us have sought and received government resources through one agency or another who value the lives of our sons and daughters, fundamentally, we turn to one another, to neighbours and friends for life and sustenance. The Ubuntu Initiative consists of parents and friends of particular individuals who have a developmental disability. We come together to imagine and to create, with these individuals, a different and more hopeful future, rooted in gentleness, interdependence, and deep friendship. All who share such imaginings and aspirations, particularly those who long for a more abundant and life enhancing future for their own son or daughter, are welcome to join us.

Our goal is to create a context, a community of friendships, that will endure overtime "where the sharing of the same truth binds us together " (i.e. the experience of collaborating with particular individuals who have a developmental disability) in ways that bring life to us all. Ubuntu is a South African Zulu word meaning: "My humanity is inextricably bound up in your humanity."

Objectives

I. **Engagement with families** who have sons and daughters who are labelled with a developmental disability.
II. **Forming alliances** with individuals and groups and organizations of like-mind.
III. Among all involved **increasing our capacity for gentleness, interdependence and deep friendship.**
IV. **Creating opportunities for learning.**

I. The Central Work – Engagement with Families

The central work of The Ubuntu Initiative, the place where we focus our energies as families, is to collaborate with our sons and daughters and with each other as families in order to bring life to us all. This leads us to:

a) listen deeply to our sons and daughters,
b) reflect on what our hearts and minds are showing us to do,
c) work with each other in strengthening our relationships with our sons and daughters,
d) deepen the actions we take with and for them and with and for ourselves,
e) expand the connections and opportunities for fostering relationship and promoting friendship within the wider community and among us all.

II. Creating the Context for the Central Work with Families and Individuals - Forming Alliances

We desire to be friends with one another. We desire to hold our sons and daughters within the realm of friendship. The concrete expression of this desire is to find a vessel or container (a context) within which people who share this truth are compelled to join together to seek this common purpose. We do envision some form of collaborative, alliance, association or consortium with individuals, groups and organizations who share our central truth. We have learned, that, before all else, faithful relationships of mutuality and love are essential to human thriving inclusive of and centred by our sons and daughters who have been labelled with a developmental disability.

III. Increase our capacity for gentleness, interdependence and deep friendship

We want for ourselves and for those involved with us to be clear on our desire to build a culture of gentleness, interdependence and deep friendship. This is primary in our work together. To be connected to the broader community is important but secondary to the fundamental need and desire to hold close and live these values to the utmost.

One of the specific expressions of this pursuit is through connection with Gentle Teaching International. Gentle Teaching is based on a psychology of human interdependence. It asks caregivers to look at themselves and their spirit of gentleness to find ways to express warmth and unconditional love toward those who are the most disenfranchised from family and community life.

IV. Creating the Opportunities for Learning.

We are committed to a process of on-going learning. We achieve this partially through:

- Regular core group meetings
- Involvement in other Family Group gatherings
- A mentoring process for those called to be facilitators
- Monthly Evenings of Reflection titled A Gathering
- Day long workshops geared to topics of interest for paid supporters, families, individuals who are disabled, ordinary community members.
- Creating and/or being part of study sessions with people who share our truth
- Participating in various conferences and workshops where themes are coherent with what we are about as a little group
- Co-sponsoring with other groups and organizations events in such areas as Gentle Teaching, community building, the L'Arche philosophy, the work of John Macmurray, etc.
- Engagement with faith communities particularly in the pursuit of social justice
- Encouraging each other to write and to share our writing
- Identifying books, articles, poems, audio visual resources
- Producing multi-media presentations via small videos – home grown or professionally done.

How to Contact Us If you are interested in being part of The Ubuntu Initiative, please contact Peter Dill at 416-910-0770 or via email peterdill@rogers.com